

Mortality

ANNUAL REPORT

FY 2009

This is the eighth of a series of annual reports on mortality, mortality trends and related information pertaining to the health and quality of care received by individuals served by the Connecticut State Department of Developmental Services. Reports focus on an analysis of mortality data and specific findings resulting from the Connecticut DDS mortality case review process. Reports are scheduled for publication March of each year.

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CT DDS Mortality Report

SECTION ONE OF THIS REPORT:

CT DDS MORTALITY REVIEW PROCESS

This section describes the CT DDS Mortality Reporting and Review Process.

SECTION TWO OF THIS REPORT:

ANALYSIS OF ALL CT DDS MORTALITIES

This section includes information and data concerning all deaths of individuals served by DDS who were listed in the CT DDS data base and died during the 2009 fiscal year (July 1, 2008- June 30, 2009) including death rates and life expectancy.

SECTION THREE OF THIS REPORT:

DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

This section includes information and analysis of data generated for the 133 deaths reviewed by the DDS regional review committees and Independent Mortality Review Board (IMRB) for the period of July 1, 2008 – June 30, 2009.

SECTION FOUR OF THIS REPORT:

MORTALITY TRENDS CT DDS

This section provides an analysis and synthesis of CT DDS mortality data over time.

SECTION FIVE OF THIS REPORT:

LEADING CAUSES OF DEATH

This section presents CT DDS leading cause of death data.

SECTION SIX OF THIS REPORT:

BENCHMARKS

This section presents and compares CT DDS, National, and State mortality statistics and leading cause of death information.

SECTION SEVEN OF THIS REPORT:

SUMMARY MORTALITY CASE REVIEW FINDINGS

This section includes information on the findings identified through the DDS mortality review process and examples of quality initiatives implemented as a result of the CT Mortality Review Process.

Appendix: Includes demographic information on the population served by the CT DDS

This report represents a review of the period between July 1, 2008 to June 30, 2009.
Data in this report was obtained from the CT DDS Database system.

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Executive Summary 2009 Report

- There were 188 deaths resulting in a crude mortality rate of 12.07/1000
- The strongest predictors of mortality are age, mobility status, the need for special assistance when eating, and the amount of supervision provided
- Women served by DDS continue to have a higher mortality rate
- The average life expectancy of people with ID is 57.1 years
- Starting early in the fifth decade of life there is a progressive increase in the mortality rate for people with intellectual disabilities
- People with intellectual disabilities have a decreased life span as compared to the general population which may be related to the onset of multiple chronic and acute co-morbidities at a younger age
- Mortality is highly related to the level of intellectual disability, the greater the level of disability the higher the mortality rate
- Heart disease continues to be the leading cause of death in the CT DDS population (29.9%)
- Respiratory disease including aspiration pneumonia/ pneumonia accounted for 36.8 % of all deaths
- The incidence of deaths related to cancer in the DDS population (7.4%) is lower than the national (23.1%) and state (23.6 %)
- Accidental deaths continue to occur at a rate below that of the general state and national population
- The average age of death for people with Down syndrome is 57.2 years
- Respiratory failure was the leading cause of death for people with Down syndrome
- The CT DDS mortality data suggest enteral feedings do not prolong survival in people with intellectual disabilities
- 68% of people who required enteral feedings died within two years of tube placement usually due to aspiration pneumonia
- The “aging in place” phenomenon continues to be a leading risk factor as individuals served by DDS become older and more disabled over time
- Mortality benchmarks established in the CT DDS and MA DDS Mortality Reports demonstrate distinct similarities and show trends within the ID population that are not present in the general population

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CT DDS MORTALITY REVIEW

An important component of the quality and risk management systems present within DDS involves the analysis and review of deaths to identify important patterns and trends that may help increase knowledge about risk factors and provide information to guide systems enhancements. Consequently CT DDS continues to embrace a planned organization wide approach to design performance measurement, analysis and improvement by collecting information pertaining to the deaths of all individuals served by the department. The CT DDS mortality review system has proven to be a valuable quality assurance mechanism providing information to trigger corrective action and reduce future risk.

The CT DDS mortality review process provides a retrospective analysis

THAT

- assures compliance with standards
- reduces adverse events
- leads to ongoing improvement

AND GENERATES

- changes in policy & procedure
- protocol development
- practice standards
- focused training
- systems improvement strategies

CT DDS DEATH REPORTING PROCESS

Per State of Connecticut Executive Order No. 25, the Department of Developmental Services shall report all deaths of persons placed or treated under the direction of the Commissioner of the Department of Developmental Services to the Office of Protection and Advocacy whether or not abuse or neglect is suspected or contributed to the individual's death.

The CT DDS death reporting process is a dynamic process that ensures that all deaths are immediately reported to the department and death report forms submitted to department within 24 hours of the death notification.

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SECTION ONE: CT DDS MORTALITY REVIEW PROCESS

CRITICAL COMPONENTS OF THE CT DDS MORTALITY PROCESS:

- Uniform death reporting system
- Screen individual death reports with standard information
- Standardized mortality review process (regional and state)
- Medical professionals participate in the process
- External stakeholders included in the review process
- State level interdisciplinary/independent mortality review board (IMRB) aggregates mortality data over time to identify trends
- Direct link between mortality findings and improvement
- Publically report and document mortality information (Annual CT DDS Mortality Report)

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Section One Continued

Connecticut law (which comprises statutes and executive order) currently requires CT DDS to review the death of anyone for whom it has direct or oversight responsibility for medical care. The review must cover the events, overall care, quality of life issues, and medical care preceding the death to assure that a vigorous and objective evaluation and review of the circumstances surrounding untimely deaths takes place. CT DDS has established a two tier mortality review process as part of its quality assurance system to trigger corrective action and reduce future risk for people. As noted below, the two tier system includes a regional mortality review committee and Independent Mortality Review Board. In addition, the mortality process includes a Medical Desk Review by trained Nurse Investigators and a final review of all IMRB cases by the CT DDS Commissioner and Director of Health and Clinical Services (IMRB Chair).

The mortality review process seeks to address the following questions:

- Was the death anticipated or unexpected?
- Could this death have been prevented?
- Are there systems issues identified in the course of the review?
- Are there case specific issues identified in the course of the review?
- What actions should DDS take to improve the health and safety of consumers?

Regional Mortality Review Committee

Criteria for Review

Any death where the department bears direct or oversight responsibility for medical care.

The CT DDS does not review the deaths of individuals who live at home with their families or who were placed by their family/guardian into a licensed nursing facility.

Independent Mortality Review Board

Criteria for Review

- Determined necessary by the regional mortality review committee
- Medical, health or residential care concerns
- Post mortem examination
- Suspicion of abuse/neglect, etc.
- Ongoing abuse/neglect investigation

Assume immediate jurisdiction and conduct an expedited review when determined necessary by the Commissioner or the OPA Executive Director if it is likely that the death occurred because of abuse or neglect or at the request of the Director of Quality Assurance and/or the Director of Health and Clinical Services.

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Section One Continued

Nurse Investigators Medical Desk Review

In addition to the regional mortality review committees and the Independent Mortality Review Board, the DDS death reporting and mortality review process requires that all deaths are reported to a **Nurse Investigator** (NI) who is assigned to the DDS Investigations Division. The Nurse Investigator conducts a **Medical Desk Review** (MDR), an abbreviated mortality review to determine the need for an expedited, comprehensive review by a regional mortality committee and/or the Independent Mortality Review Board or if an immediate investigation of the death by another state agency is warranted.

Role of the Nurse Investigators

The Nurse Investigator will forward the Medical Desk Review and associated documents to the DDS Director of Investigations, DDS Director of Health Services (Chair of the Regional Mortality Review Committee) and the DDS Director of Health and Clinical Services (Chair of the Independent Mortality Review Board) when:

- Abuse or neglect is suspected according to DDS abuse/neglect policies and procedures
- Systems deficiencies are identified or suspected
- For routine mortality review as defined in DDS procedure

Independent Mortality Review Board Membership

Members of the Independent Mortality Review Board (IMRB) are appointed by the CT DDS Commissioner and Executive Director of the CT Office of Protection and Advocacy for DD and include:

- DDS Director of Health and Clinical Services (Chair)
- DDS Director Division of Investigations
- DDS Director Division of Quality Management
- Associate Medical Examiner
(State Office of the Chief Medical Examiner)
- Community based physician
- State Office of Protection and Advocacy
- State Department of Public Health
- Executive Director private provider agency
- Parent representative

Regional Mortality Committee Membership

Members of the Regional Mortality Review Committees are appointed by the regional or training school (STS) Director and include:

- DDS Regional Health Services Director (Chair)
- Medical Director (for STS campus)
- Non DDS registered nurse
- Non DDS consumer advocate
- DDS residential manager
- DDS Assistant Regional Director
- DDS abuse/neglect liaison
- Family representative

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SECTION TWO: ANALYSIS OF ALL CT DDS MORTALITIES
(JULY 1, 2008 – JUNE 30, 2009)
NUMBER OF DEATHS REPORTED = 188

Overall Mortality Rate

During the 12 month time period between July 1, 2008 and June 30, 2009 a **total of 188** individuals supported by CT DDS passed away **resulting in a mortality rate of 12.07** (Figure 1 & 2 below). Both the number of deaths and mortality rate decreased in FY 09.

Figure 1

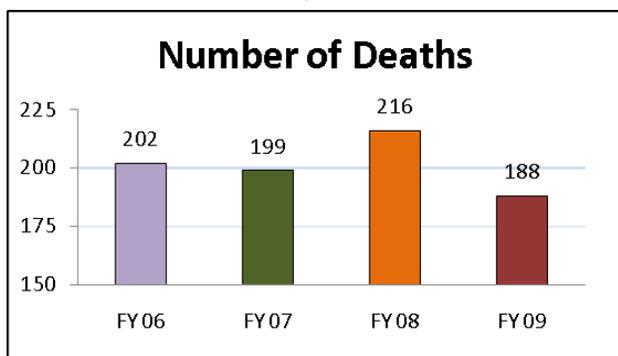
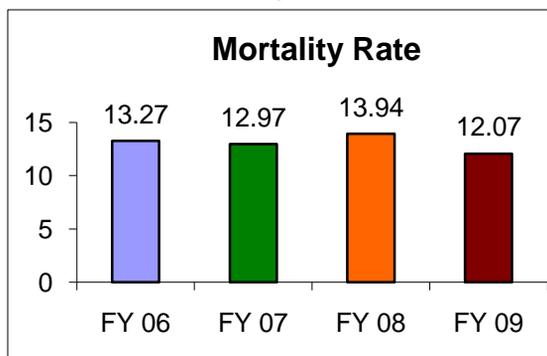


Figure 2



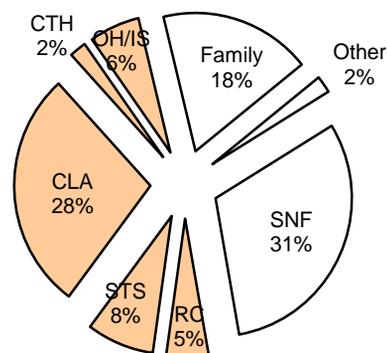
Mortality and Residence

As can be seen in Figure 3 (to the right) fifty-one percent of deaths occurred in settings that were not operated, funded or licensed by CT DDS.

Figure 3

Residence at Time of Death

	% Deaths	% DDS population
SNF	31	3
CLA	28	25
Family	18	50
STS	8	3
OH/IS	6	13
RC	5	2
CTH	2	3
Other	2	2



SNF = skilled nursing facility; RC = regional center; STS = Southbury Training School; CLA = community living arrangement (group home); CTH = community training home; OH/IS = own home/individualized supports; Family = live with family at home.

Shaded areas represent settings operated, funded or licensed by CT DDS.

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Figure 4

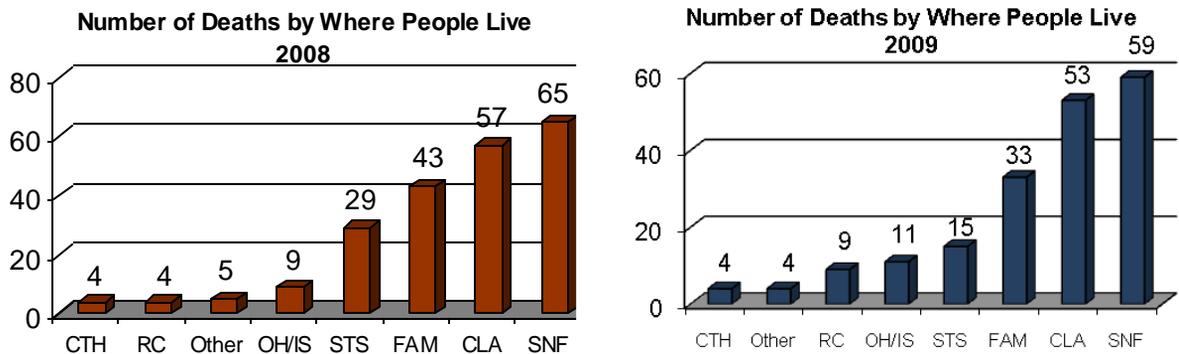


Figure 4 (above) depicts the actual number of deaths by where people live. In line with last year's data the greatest number of deaths occurred in skilled nursing facilities followed by CLA's, family homes and STS. Of note: Sixty-three (63%) of the people DDS supports live in family homes or in their own home with individualized supports, 25% in group homes (CLA's) and only 3% in skilled nursing facilities.

Figure 5

Mortality Rate by Where People Live

No. Deaths per 1000 people
FY 2009

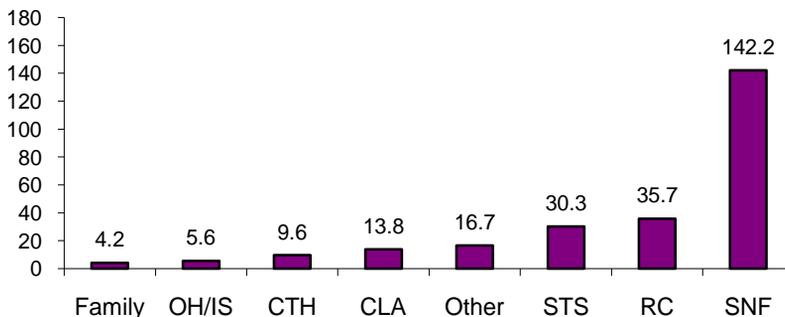


Figure 5 (left) depicts the number of people who died for every 1000 people served by type of support.

Of note: In general, individuals supported by DDS who live in skilled nursing facilities and at STS tend to be older, are more impaired both cognitively and functionally. They also have considerable health co-morbidities.

The estimated 2004 crude mortality rate in nursing homes (SNF) for the U.S. population is 363.5 per thousand.⁷⁴

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Mortality and Residence

Family Home: People who live with their family or independently without significant residential DDS supports represent 50% of the DDS population. However, in FY 2009 only 33 deaths (18% of all deaths) occurred in a family home with an associated mortality rate of 4.2. All CT DDS deaths of children were for those who lived with their families. Twenty-four of the 33 people died in a hospital or hospital emergency department.

CLA: These settings serve people with varying levels of intellectual disabilities who require 24 hour supervision for their health and direct care supports. Health supports are generally less intensive than licensed nursing homes (SNF) or campus settings which may explain a lower mortality rate of 13.8 for this type of residence. In FY 2009, 53 or 28.1% of all deaths occurred in CLA's compared to 26.4% in FY 08. Thirty-eight of the 53 people died in a hospital or hospital emergency department.

CTH: There were only 4 reported deaths in the community training homes in line with the 4 deaths reported in FY 08. These deaths were anticipated and related to an existing condition. The CTH mortality rate of 9.6 was greater than the mortality rate for people living at home with their family or people living in their own home or independently with supports. People living in CTH's represent 2.7% of the DDS population and accounted for 2% of the reported deaths. Two of the 4 people died in a hospital or hospital emergency department.

OH/IS: People receiving intermittent individualized supports in their own homes in most cases are less medically involved than people living in other settings and therefore, do not require 24 hour direct supports. Only 6 percent (6%) of reported deaths occurred in this environment compared with 4% last year. Seven of the 11 people died at their home the rest (4) died in the hospital or hospital emergency department.

STS: This larger campus setting serves a population of older adults (average age of 61.2 years). Many of these individuals present with severe to profound intellectual disabilities and have multiple co-morbidities. The higher mortality rate of 30.3 is not surprising in this medically fragile population. Fifteen deaths were reported at STS this past fiscal year representing 8% of all DDS deaths. Last year the Training School accounted for 13.4% of all deaths. Eight of the 15 people died in a hospital or hospital emergency department.

RC: Similar to people living at the STS campus the majority of people supported in publically operated regional centers have multiple co-morbidities that require 24 hour direct support and nursing supervision. Less than 2% of DDS consumers reside at DDS regional centers. Only 9 RC residents died in FY 2009 accounting for less than 5% of all DDS deaths. One of these individuals were pronounced at the regional center the other 8 died in a hospital or hospital emergency department.

SNF: Only 2% of people served by CT DDS live in a skilled nursing facility. This older (average age 65.1 years) and medically fragile population accounted for 59 or 31% of all reported deaths. People living in licensed nursing facilities had the highest mortality rate 142.2 per thousand. Eighteen percent (18%) of all DDS consumers over 65 years of age live in a skilled nursing facility. It is important to note that 34 of the 59 people died in a hospital or hospital emergency department.

- Community Living arrangement (CLA): 24 hour support is provided with staff in small group home settings people share an apartment or house also known as a group home.
- Community Training Home (CTH): A family setting that is not the consumer's own family. CTH provider has received training and is licensed by DDS to provide services.
- Own Home/Individualized Supports (OH/IS): Minimal hours of support to live in their own home. Staff support may be from a few hours a day to only a few hours a month depending on the support needs of the person.
- Southbury Training School (STS): 24 hour support is provided in a large campus setting serving a population of older adults with severe to profound intellectual disabilities.
- Regional Center (RC): Regional Centers are facilities for over 16 people that provide 24 hour staffing.
- Skilled Nursing Facility (SNF): a Department of Public Health licensed nursing facility for people requiring skilled nursing level of care not licensed or funded by the Department of Developmental Services also known as a nursing home.

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Mortality and Gender

Table 1

Mortality Rate by Gender - 2009

GENDER	All Individuals Served by DDS	Total Number of Consumers	No. Deaths	Percentage of Deaths	Rate (No. Deaths Per 1000)
Men	57%	8,825	103	54.8%	11.54
Women	43%	6,565	85	45.2%	12.78
Total	100%	15,390	188	100%	24.32

In FY 2009 both the number of males and females who died within the DDS mirrored that of the gender distribution of those people served by the department.

Figure 6

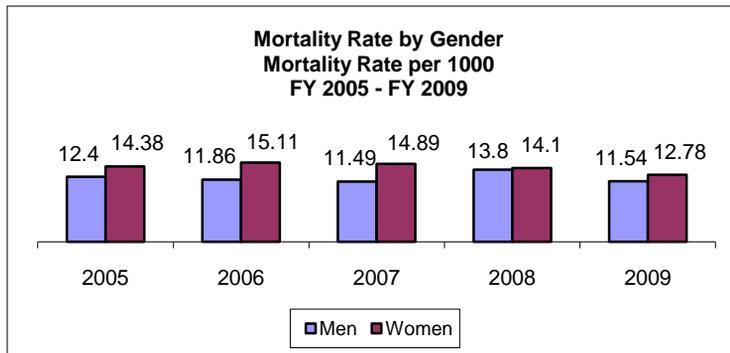
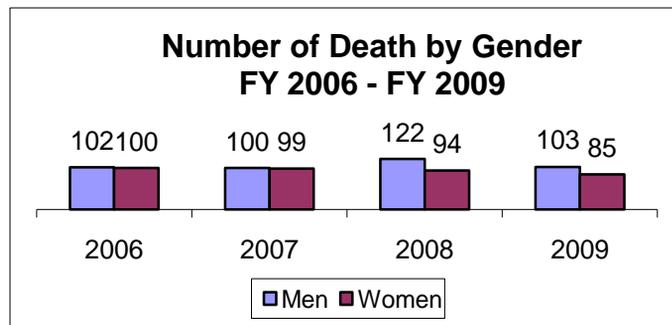


Figure 7

Although there are year to year variations in the actual number of deaths by gender, the data consistently demonstrate that more men than women die each year and that women have a higher mortality rate.

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Mortality and Age

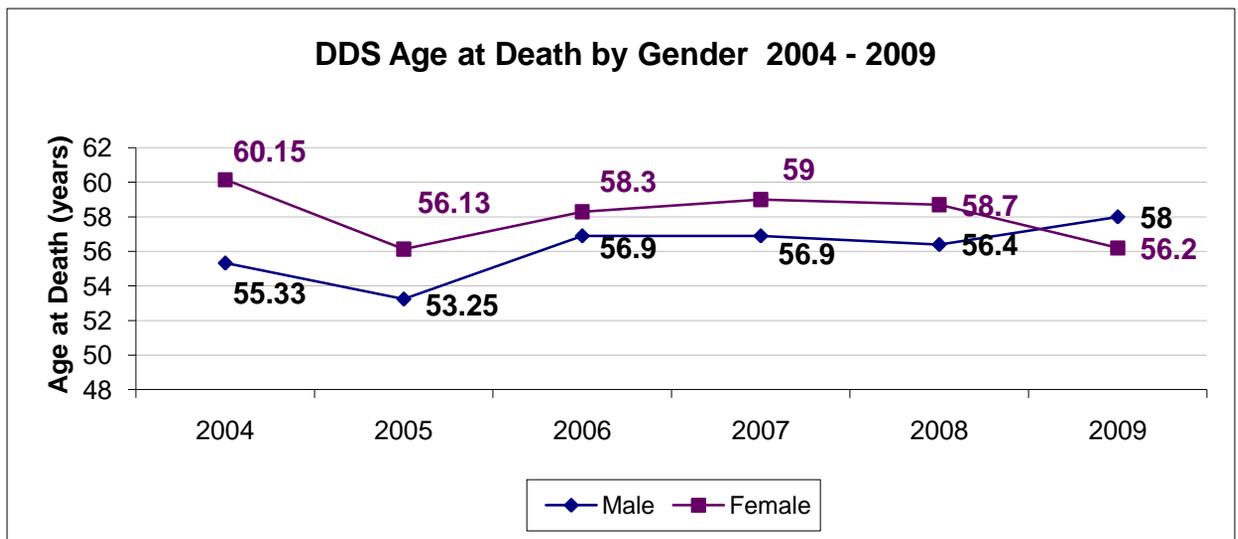
Table 2

Age of Death

Year	Men	Women	Average Age
CT DDS FY 2009	58	56.2	57.1
CT DDS FY 2008	56.4	58.7	57.4

CT DDS FY 2007	56.9	59	57.9
CT 2007	71.8	78.8	79.5
US 2007	75.3	80.4	77.9

Figure 8



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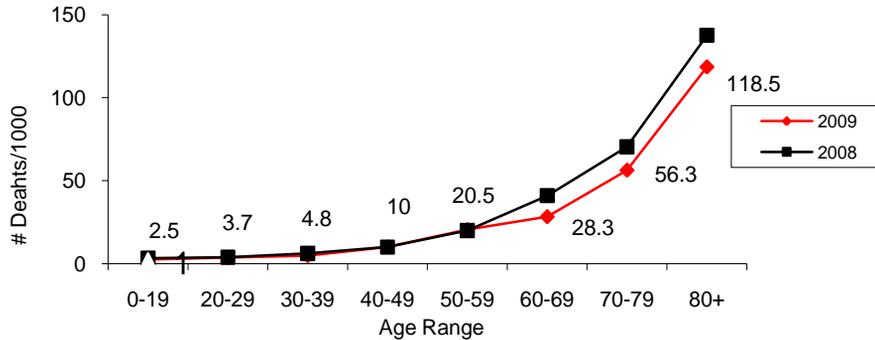
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Figure 9

Mortality Rates by Age Range

No. Death per 1000 People
FY 2008 and FY 2009



The relationship between **age** and **mortality** demonstrates the expected trend, with the mortality rate increasing as people served by DDS get older. As seen in Figure 9, there is an increase in the mortality rate that begins early in the fifth decade of life that continues to increase with advancing age. This finding is consistent with previous CT DDS mortality rate by age data.

Table 3

Mortality Age Range Distribution Data FY 2009

AGE RANGE	# OF DEATHS	% OF DEATHS	MORTALITY RATE
Age 0-19	9	4.8%	2.5
Age 20-29	12	6.4%	3.7
Age 30-39	10	5.3%	4.8
Age 40-49	26	13.8%	10
Age 50-59	46	24.5%	20.5
Age 60-69	34	18.1%	28.3
Age 70-79	26	13.8%	56.3
Age 80+	25	13.3%	118.5
TOTAL	188	100%	

Mortality statistics for the DDS population in Table 3 reveal a progressive increase in the mortality rate as the age range increases. Above the age of 60 years the number of deaths declines as the number of individuals supported by DDS declines.

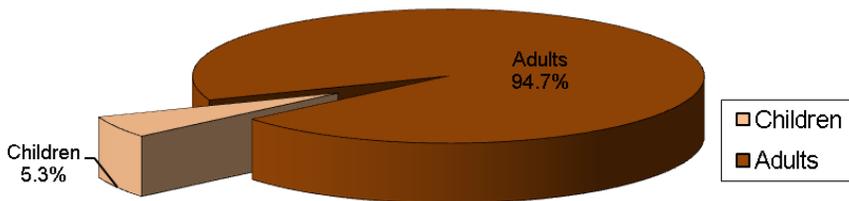
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Figure 10

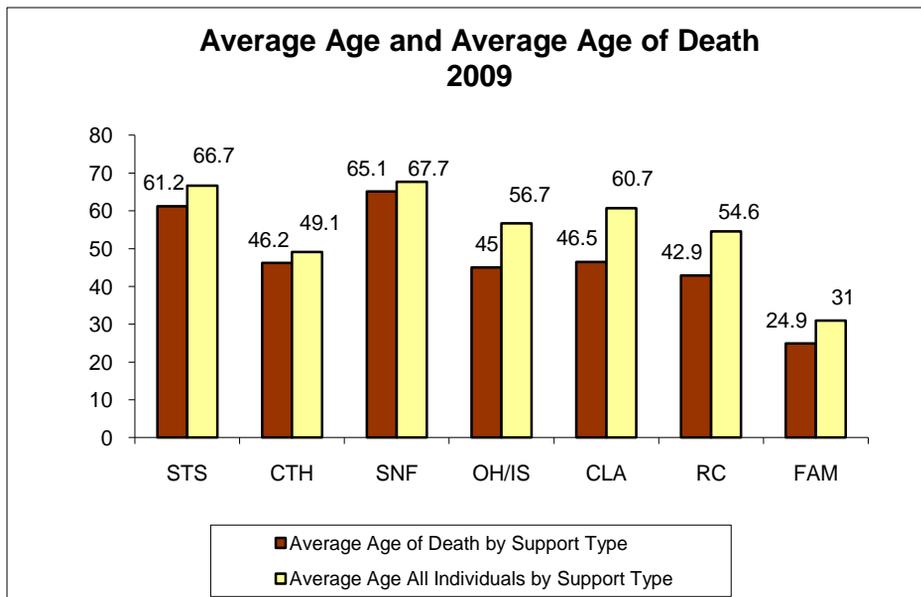
Deaths of Children and Adults



Children < 19 Years of Age

In FY 09 nine children died and in every case these children lived at home with their family.

Figure 11



The average age of death for individuals living in nursing facilities and the Training School are higher than for the rest of the DDS population that receive other types of support. And although this finding is of interest there are many unique population specific variables related to a specific support type that may account for it. For example, the lower age of death in the regional centers may be a result of the small number of deaths (9) that occurred in that particular setting. Also almost all of the children served by DDS live at home with their family that translates into a much lower average age and age of death. Excluding children the average age of death in the CT DDS population is 59.4 years.

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SECTION THREE: DATA GENERATED BY THE CT DDS MORTALITY REVIEW PROCESS

IMPORTANT PLEASE NOTE:

THE INFORMATION PRESENTED IN THIS SECTION SUMMARIZES ONLY THOSE DEATHS THAT WERE REVIEWED BY THE REGIONAL COMMITTEE AND/OR STATE INDEPENDENT MORTALITY REVIEW BOARD IN FY 2009

THEREFORE THE MORTALITY DATA WILL DIFFER FROM THE INFORMATION PRESENTED AND DISCUSSED IN SECTION TWO OF THIS REPORT

DDS MORTALITY COMMITTEE/BOARD REVIEWS = 133 cases (of total 188 deaths)

Community Hospice Support

The concept of end of life planning including hospice care has been embraced by the CT DDS and is routinely requested and provided for individuals served by DDS who live in all settings, including regional centers, Southbury Training School, community living arrangements, community training homes, own home/individualized supports and family homes. This includes state of the art palliative and hospice care to provide end of life support, hope and comfort to individuals either in the home or in a hospital setting.

The use of hospice services allowed CT DDS to support people through the final stages of a terminal illness while remaining in their current residence. Forty-six individuals received hospice services: 46% lived in group homes, 22% lived in a nursing home, 19% lived at the training school, 9% lived at the regional campus, 2% lived in a community training home and 2% lived in a hospital. The average age of death for people receiving hospice services was 62.2.

Forty-six people (35% of all reviewed deaths) received hospice supports

Autopsies/Post Mortem Examinations

Autopsies are performed by the Office of the Chief Medical Examiner (OCME) for those deaths in which the OCME assumes jurisdiction or by hospital based pathology departments when DDS requests and the family consents to the autopsy.

GUIDELINES FOR REQUESTING AUTOPSIES

- certain sudden or unexpected deaths in which the cause of death is not due to a previously diagnosed condition or disease
 - deaths involving an earlier accident or trauma
 - deaths involving questionable contributing factors
 - cases involving an allegation of abuse or neglect

Number of post mortem examinations performed:	14 (11% of reviewed deaths)
Number of post mortem examination performed by CT OCME:	9

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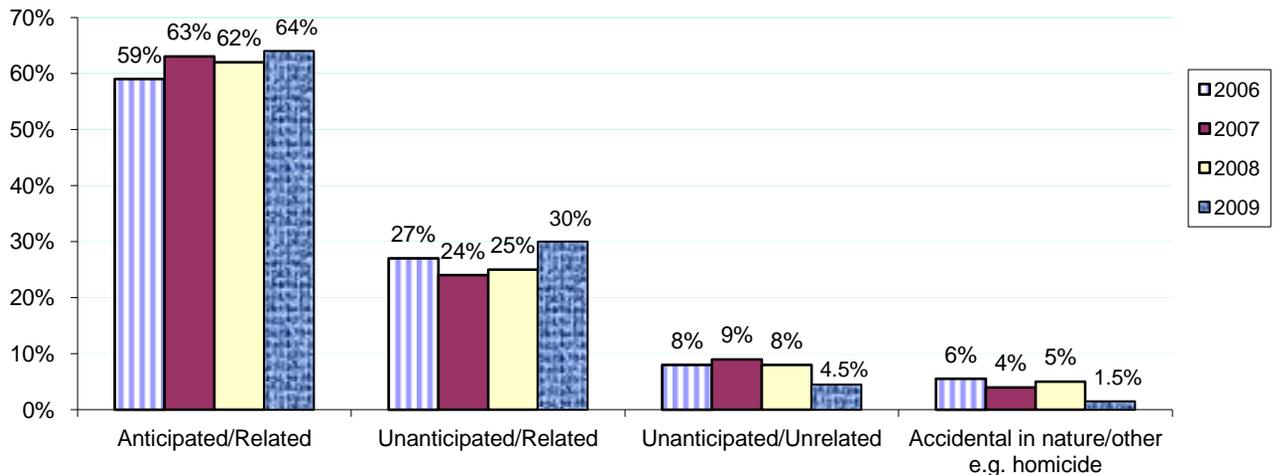
Predictability

Analysis of the mortality review data indicates a relationship between an individual's pre-existing diagnosed medical condition(s) and his/her immediate cause of death (see Figure 12 below). In ninety-four percent of all deaths, an individual's immediate cause of death was related to a known or previously diagnosed medical condition/disease. For example: an individual who died as a result of a cardiac arrest had a medical history that included coronary artery disease.

- Death was anticipated and related to a preexisting diagnosis: 64%
- Death was unanticipated but related to a preexisting diagnosis: 30%
- Death was unanticipated and unrelated to a preexisting diagnosis: 6% (includes accidental deaths)

Figure 12

Predictability of Death 2006 - 2009



OF NOTE:

For individuals living in skilled nursing facilities the condition(s)/diagnoses that contributed or was the immediate cause of death was known to health care providers 100% of the time.

For the majority of individuals over 65 years of age their death was anticipated due to or related to an existing medical condition. The CT DDS data illustrates that for people over the age of 65 the cause of death was directly related to a pre-existing or known medical condition 98% of the time. This finding seems to support the conclusion that age and specific pre-existing medical conditions are very reliable predictors of death in the ID population.

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Context: Manner of Death for Cases Reviewed

According to Connecticut State law, the Office of the Chief Medical Examiner (OCME) determines the cause of death and the manner of death: **natural, accident, suicide, homicide** or **undetermined**.

In the State of CT deaths for which the OCME does not assume jurisdiction, pronouncement is made by a private physician. In these cases the manner of death must be classified as natural. According to state statute any other manner of death must be determined by the OCME.

Of the 133 cases reviewed during FY 09, 130 (97%) were classified as due to natural causes. The other 3 cases were determined to be the result of an accident or undetermined.

Table 4

FY 09 Manner of Death

<i>Manner of Death</i>	<i>No.</i>	<i>Percent</i>
<i>Natural</i>	<i>130</i>	<i>97%</i>
<i>Accident</i>	<i>2</i>	<i>2%</i>
<i>Undetermined</i>	<i>1</i>	<i>1%</i>
<i>Total</i>	<i>133</i>	<i>100%</i>

Cause of death for the deaths determined by the CT OCME to be accidental in nature:

Fall	(1)
Choking	(1)

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UNANTICIPATED/UNRELATED DEATHS:

Of the 8 deaths that were unanticipated and not related to a known condition 2 were accidental in nature, 1 was undetermined and 5 were due to natural causes. The causes of mortality for the (5) unanticipated deaths due to natural causes were: Cardiac arrest (3); septicemia (1); intracerebral hemorrhage (1).

ACCIDENTAL DEATHS

Of the two cases of accidental deaths, one was a result of a fall and the other was the result of a choking episode.

UNDETERMINED DEATH

In the one case of undetermined death the final cause of death per autopsy was "undetermined cause of death in setting of esophageal and gastrointestinal dilation".

DNR

Per Connecticut State Statute, CT DDS has an established procedure which requires that **specific criteria must be met along with a special review process** for all withholding cardiopulmonary resuscitation (DNR) orders to be issued/implemented for persons who are placed and treated under the direction of the Commissioner of DDS. Documentation regarding end of life planning and withholding of cardiopulmonary resuscitation is required per CT DDS policy.

Do Not Resuscitate (DNR) orders are medically indicated when an individual's attending physician and another physician (second opinion) have diagnosed that an individual is in the final stages of a terminal disease or condition, or is permanently unconscious based upon appropriate tests and studies. This confirmation by the attending physicians that an individual has a terminal disease or condition is reviewed by DDS medical staff (Health Services Directors and in some cases Director of Health and Clinical Services).

For the 133 mortality cases reviewed in FY 2009

.....
92 cases had a DNR order in place
92% of the DNR orders were formally reviewed by DDS
100% of the DNR orders met the established DDS medical criteria
.....

In 8% of all cases in which a DNR was ordered by a medical practitioner DDS was not notified prior to the implementation of the DNR order as is required by DDS procedure. However, the DDS mortality review process determined that in every case the medical criteria to support the decision to initiate the DNR was met.

OF NOTE: Fifty-nine percent (59%) of DDS consumers residing in *skilled nursing facilities* had a DNR order in place at the time of their death.

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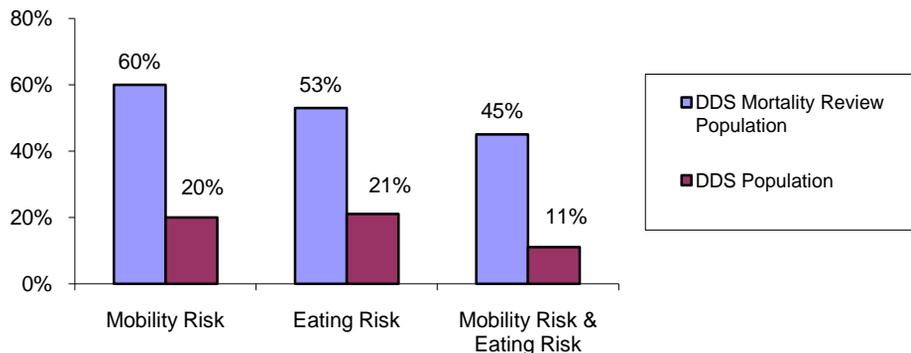
Section Three Continued

Risk Factors

Mobility impairments and dysphagia/swallowing risks are well known risk indicators that place individuals at significantly higher risk of morbidity and mortality. CT DDS mortality data has consistently demonstrated that people who require the need for special assistance when eating and those who cannot ambulate without assistance have a greater mortality rate. Therefore the CT DDS mortality review process carefully analyzes the presence or absence of these two risk indicators. Once again the FY 2009 data illustrates the relationship between these risk factors and mortality (see Figure 13 below).

Figure 13

Risk Factors 2009



It is well documented in the literature that the more compromised an individual's level of mobility, the greater the likelihood of death.^{5,7,31,34} CT mortality data supports the importance of mobility as an indicator of morbidity and mortality. In FY 2009, eighty (60%) of the deceased did not ambulate independently. CT mortality data also supports the importance of dysphagia/swallowing risks as an indicator of morbidity and mortality. In FY 2009, seventy (53%) of the deceased were diagnosed with dysphagia.

MORTALITY REVIEW POPULATION ONLY

60% did not ambulate independently
53% did not eat independently

* DDS POPULATION

20% do not ambulate independently
21% do not eat independently

*Does not include family homes

Of note: Information regarding the presence and/or risk of silent aspiration is not available and therefore is not included in the eating risk factor data.

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Section Three Continued

Mortality and Complex Health Conditions

Another important factor which seems to affect life expectancy of individuals with intellectual disabilities is the presence of one or more complex health conditions.

As expected, individuals who require intensive (24 hour per day skilled nursing/medical) supports due to co-morbid conditions such as cerebral palsy, epilepsy, genetic syndromes, severe intellectual disability, mobility, eating dysfunction, and/or enteral feedings had a higher mortality rate than individuals who had fewer health concerns.

Table 5

Relationship Between Mortality and Complex Health Conditions

	FY 09	FY 08	FY 07	FY 09	FY 08	FY 07
	% of	% of	% of	Death	Death	Death
	All Deaths	All Deaths	All Deaths	Rate	Rate	Rate
24 HOUR SKILLED NURSING SUPPORT:	46%	46%	44%	70.9	73	70.8
24 HOUR NURSING SUPPORT:	30%	33%	37%	13.4	12.2	13.8
LESS THAN 24 HOUR NURSING SUPPORT:	23%	21%	19%	4.5	5.7	4.5

As noted in the table above, the death rate for those individuals who receive 24 hour skilled nursing support (living in nursing homes, the Training School and regional centers) had a mortality rate of 70.9 in FY 09. This mortality rate greatly exceeded the death rate for individuals needing 24 hour nursing support (13.4) (living in group homes and community training homes) and for those individuals requiring less than 24 hour nursing support (4.5) (living in their own home or receiving individualized supports). These findings are consistent with the FY 07 and FY 08 mortality data which also illustrate a direct relationship between the level of nursing/medical support and mortality rate. *

Table 6

Level of Intellectual Disability and Mortality Rate

	2007	2008	2009	Percent of Population
Mild	23.3	13.6	12.9	40
Moderate	27.7	15.6	13.1	30
Severe	24.1	19.9	22.3	14
Profound	24.8	28.4	29.6	9

Table 6 above illustrates the relationship between an individual's level of intellectual disability and mortality rate. There is an inverse relationship between the level of intellectual disability and the mortality rate within the DDS population. Over the years, individuals with severe or profound intellectual disabilities have a higher mortality rate than those with moderate or mild intellectual disability.

* Denotes all 188 deaths.

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Section Three Continued

Investigations

Office of Protection & Advocacy / Abuse Investigations Division

CT DDS must report all deaths to the Office of Protection and Advocacy for Persons with Disabilities Abuse Investigations Division (OPA/AID) which determines if abuse or neglect was involved in the death.

Of the 133 mortality cases reviewed by DDS, 9 cases were investigated by either the OPA/AID or the DDS through its Investigations Division where abuse or neglect is suspected to have contributed to a person's death. In several cases, deaths that were investigated by the Office of Protection and Advocacy were also referred to and investigated by the CT Department of Public Health.

<u>Disposition of OPA/AID Cases</u>	
<i>Neglect substantiated</i>	4
<i>Neglect not substantiated</i>	2
<i>Cases still open</i>	3

In 1 of the cases where neglect was substantiated, the neglect directly resulted in injuries/ incidents which directly contributed to the individual's death.

In 3 other cases where neglect was substantiated, the lack of supervision by direct care staff, delay in treatment, delay in recognition of a changing health condition, lack of programmatic safeguards and monitoring of an individual's health care status led to a chain of events that may well have contributed to the individual's death.

Department of Public Health

The CT Department of Public Health investigates the quality of care/practice by licensed practitioners and licensed healthcare facilities that include hospitals, rehabilitation hospitals, end stage renal dialysis units, outpatient surgical centers, laboratories and Medicaid certified physical therapy units.

During FY 2009 ten (10) mortality cases were referred by the regional mortality committee or IMRB to the **State of Connecticut Department of Public Health** (DPH) Health Systems Regulation Division for further investigation by the Facilities and/or the Practitioner and Licensing Section.

Disposition of DPH Investigations

The 10 cases referred to DPH generated 10 investigations

<u>Practitioner Division Investigations – (3)</u>
cases open – 0
citations, violations found - 0

<u>Facility Division Investigations – (7)</u>
cases open – 5
citations, violations found – 1

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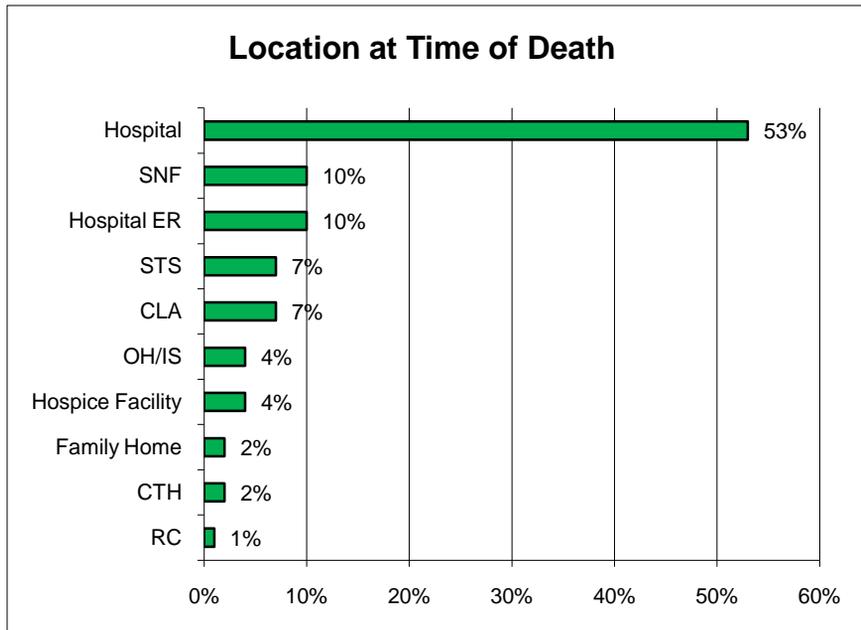
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Pronouncement of Death (Location at Time of Death)

Figure 14 below depicts the location where death was pronounced.

Figure 14



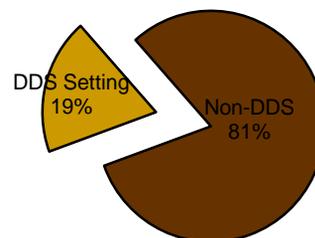
KEY: Location of Death

- Hospital = Admission to the hospital as an inpatient, death occurred in the hospital.
- Hospital ER = Evaluated in hospital ER, died in ER, while receiving treatment, not admitted to the hospital.
- All Other = Died where the person lived or worked or other community location, for example a day program. RC- regional center, STS- training school.

Figure 15

Where People Died FY 2009 Mortality Reviews

As can be seen in Figure 15 to the right, 81% of all deaths reviewed by the mortality review committee during FY 09 occurred outside of a DDS operated, licensed or funded residential setting, this represents a slight increase in the number of people dying outside of a DDS setting compared to FY 08 (80%).



SUMMARY OF MORTALITY DATA

for the 133 deaths that were reviewed in FY09

- **100%** of required cases were reviewed **Regionally**.
- **41%** of all cases were reviewed by the **IMRB**.
- **35%** of the individuals received **Hospice** supports prior to their deaths.
- **11%** of the individuals had **Autopsies** performed.
- **94%** of all deaths were **Related** to an existing medical diagnosis.
- **69%** of the individuals had a **DNR** order in place at the time of death.
- **45%** of the individuals had two **Risk Factors** (non-ambulatory and could not eat without assistance).
- **97%** of the deaths reviewed were due to **Natural** causes.
- **2** number of deaths that were classified as **Accidental**.
- **10** number of referrals to **Department of Public Health**.
- **9** number of referrals to **Office of Protection & Advocacy Abuse Investigation Division**.
- **4** number of cases **Neglect** was substantiated by OPA or DDS.

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SECTION FOUR: MORTALITY TRENDS CT DDS

For the past eight years the Connecticut Department of Developmental Services has collected, reviewed and analyzed mortality data.

Data collection has focused on mortality and residence, mortality and age, mortality and gender and leading causes and factors associated with death.

The consistency of the cumulative data/statistics from one year to the next seems to validate and support the trends and findings identified within the intellectual disability population group served by the State of Connecticut Department of Developmental Services.

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Figure 16

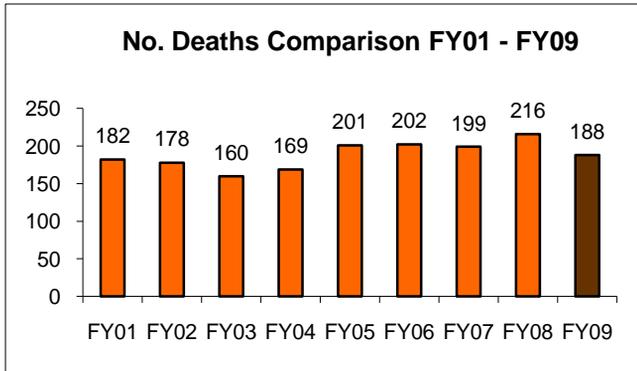
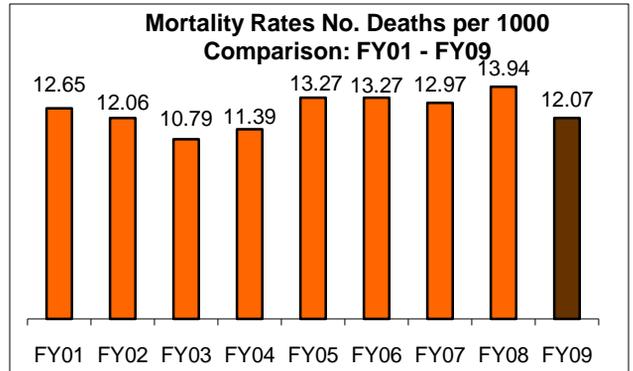


Figure 17



Figures 16 and 17 depict on an annual basis the number of deaths and the average death rate for FY 2001 - 2009 within the population served by DDS. The death rate average over the nine year period of time is 12.49/1000 people.

Figure 18

Mortality Rate by Where People Live
7 Year Trend

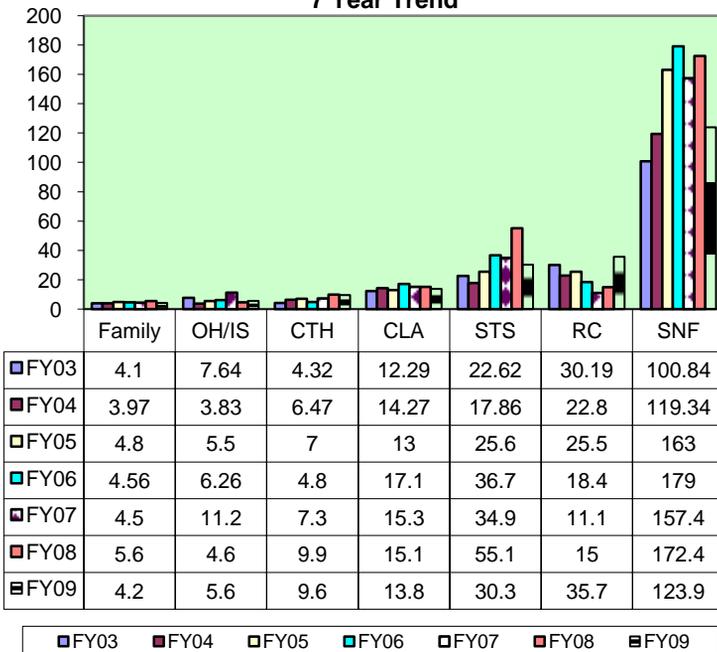


Figure 18 (to the left) compares the death rate (the number of deaths per 1000 persons served) for the past seven (7) fiscal years by type of support.

Historically, individuals residing in residences (SNF, campus) that require more intensive nursing supports and medical oversight due to their compromised health status have a greater death rate than people living in other types of settings. These data differ from other research studies which found that mortality rates are higher for people living in community based settings and lower for people with intellectual disabilities who live in congregate institutional like settings.^{21,33}

Caution must be exercised in reviewing this data since the actual number of deaths in some of these support settings are relatively small.

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Table 7

**Mortality and Gender
(2002 - 2009)**

Year	# Deaths Men	# Deaths Women	Mortality Rate Men	Mortality Rate Women
2002	92	86	11.14	13.23
2003	96	64	11.54	9.84
2004	87	82	10.47	12.57
2005	106	95	12.40	14.38
2006	102	100	11.86	15.11
2007	100	99	11.61	15.13
2008	122	94	13.8	14
2009	103	85	11.54	12.78

Over the past eight years more men died annually than women and with only one exception (2003) the mortality rate for women exceeded the mortality rate for men.

Figure 19

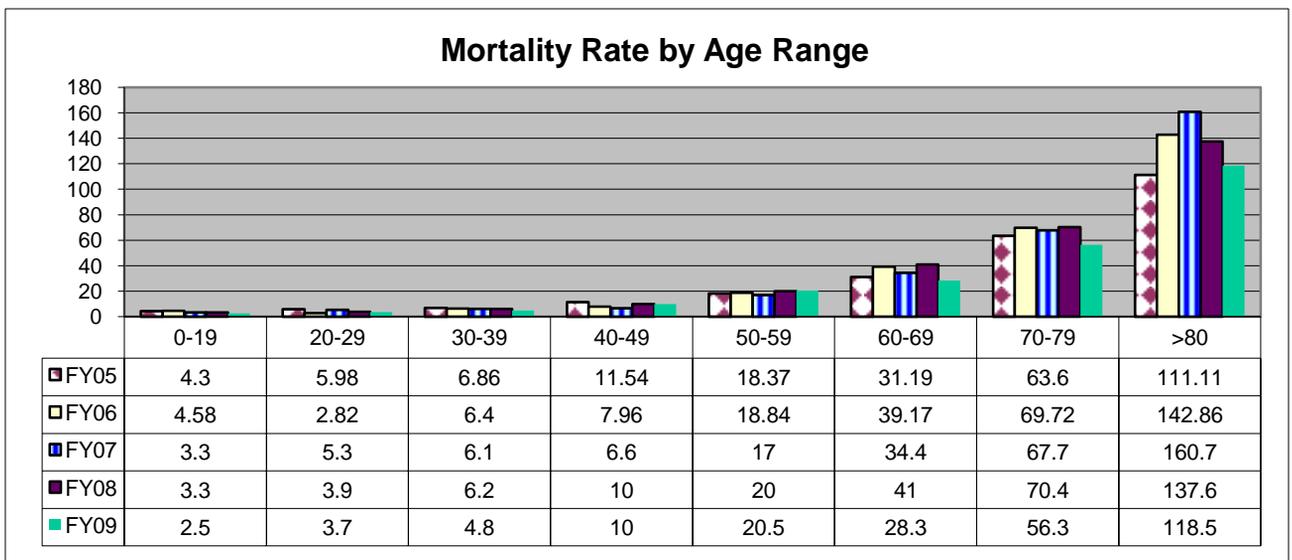


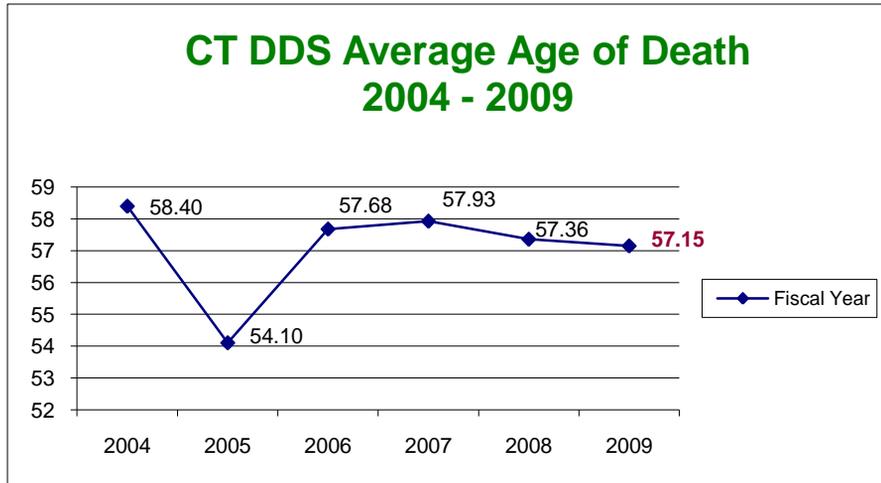
Figure 19 (above) illustrates mortality rate by age range. The data over the past five fiscal years reveals a consistent pattern of increasing mortality rates with each successive decade of life. The mortality rates increase markedly for adults who are in their fifth decade of life. The data also demonstrates that within each age range there is some fluctuation in mortality rates from one year to the next.

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Figure 20



For the last six fiscal years the average age of death has held in a tight range within the fifth decade of life.

Table 8

RESIDENCE AT TIME OF DEATH TRENDS (2002 - 2009)

	2002	2003	2004	2005	2006	2007	2008	2009
SNF	28%	30%	35%	40%	33%	33%	30%	31%
CLA	30%	27%	31%	23%	31%	29%	26%	28%
Family	19%	20%	15%	19%	18%	17%	20%	18%
STS	*	9%	7%	7%	10%	10%	13%	8%
OH/IS	3%	6%	3%	4%	4%	7%	5%	6%
RC	*	5%	4%	4%	2%	2%	2%	5%
CTH	3%	1%	2%	1%	1%	1%	2%	2%
Other	2%	2%	0%	2%	0%	1%	2%	2%
	100%	100%	100%	100%	100%	100%	100%	100%

* Data not available

Table 8 depicts the percentage of deaths within various support types over an eight year period of time.

Although there is some variability, the percentage of DDS deaths that occur in SNF's and CLA's is greater than other settings.

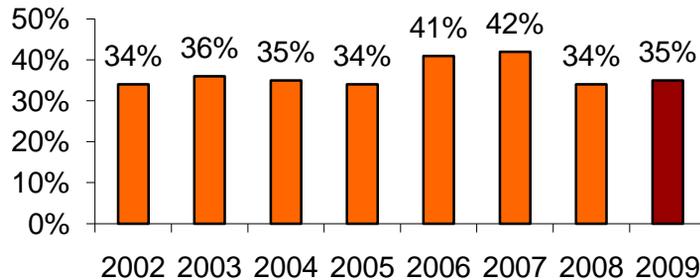
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Figure 21

Percent of Hospice Supports (2002 - 2009)



End of life planning and hospice care has been a hallmark of the CT DDS system as noted above. Where appropriate, end of life planning and support services were provided prior to death with the individual's team involved in the planning process. The continued integration of hospice supports into the person's support plan can be attributed to mortality review findings and recommendations. Case managers, nurses and other team members actively seek out hospice services in cases where death is anticipated as a result of a terminal illness.

Table 9

Location Where Death Pronounced

(FY 2002 - 2009)

Location	2002	2003	2004	2005	2006	2007	2008	2009	8 Year Total
Hospital	41	34	35	64	58	63	71	71	437
SNF	13	22	26	35	30	28	26	14	194
CLA	17	16	18	16	17	15	7	10	116
Hospital ER	10	9	4	18	14	16	9	13	93
STS	4	1	5	4	14	6	11	10	55
RC	7	11	5	3	2	1	0	1	30
OH/IS	4	4	3	4	5	3	3	5	31
Hospice	2	1	3	7	2	2	1	5	23
Other	1	1	0	1	3	3	5	4	18

Over the eight year period noted above 44% of deaths have occurred in hospitals, 20% in SNF's and 9% in Emergency Departments. It is reasonable to conclude that the stable number of deaths occurring in medical settings are due to the timely recognition of signs and symptoms of illness by non-licensed and licensed staff, and the general aging of the DDS population.

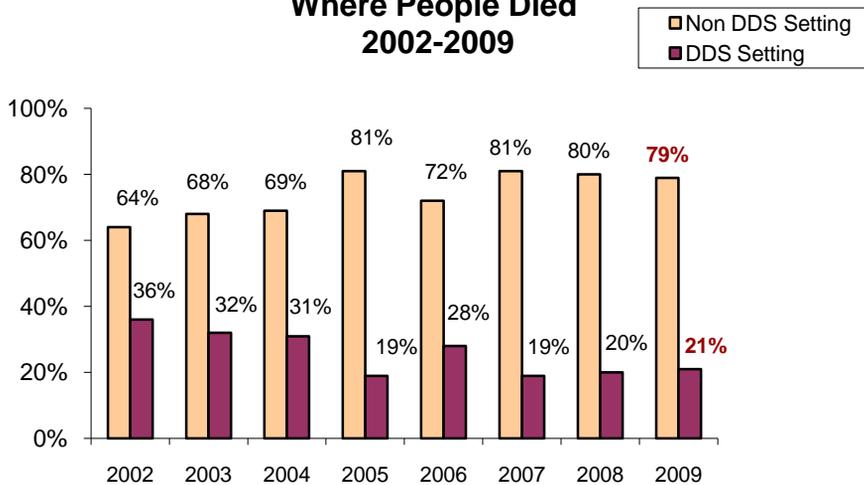
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Figure 22

Where People Died 2002-2009



The number of people served by DDS who expired in non DDS funded settings has decreased slightly in FY 2009 (79% compared to 80% in 2008). The overall increase in the number of individuals who expire in non DDS settings may be due to the earlier recognition of signs and symptoms of an individual's acute or chronic illness by direct support staff. This timely reporting of changes in health condition by staff may be a result of training which has occurred due to past IMRB findings and recommendations. In addition, 24 hour monitoring and assessment by registered nurses for many consumers receiving DDS supports has led to more timely recognition of potential and/or actual acute health conditions that result in emergency department evaluation and often hospital admission.

Table 10

Number of Autopsies (FY 2003 – FY 2008)

FY 03	28	21%
FY 04	16	16%
FY 05	20	13%
FY 06	17	12%
FY 07	11	8%
FY 08	17	13%
FY 09	14	11%

As noted in Table 10 above the number of autopsies performed vary from one review year to the next. This variation can be attributed to the number of deaths in a given year, the specific death related circumstances and requests for consent post mortems by family members. The number of post mortem examinations during FY 2009 decreased from 2008 (11% vs. 13%).

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SECTION FIVE: LEADING CAUSES OF DEATH

This section discusses cause of death data for people served by the CT DDS in calendar year 2009. The information used to determine the cause of death for each individual was gathered from the DDS Death Report Form and/or the Certificate of Death.* In addition the documented cause of death is also reviewed by the regional mortality committee and/or IMRB during the mortality review process.

Table 11

Leading Cause of Death Data CT DDS (based on the calendar year 2009)

29.9%	<i>of deaths were due to</i>	Heart Disease	<i>including</i>	Acute MI, CHF, Dysrhythmias, Pulmonary HTN, Asystole, Cardiomyopathy
13.7%	<i>of deaths were due to</i>	Respiratory Disease	<i>including</i>	Respiratory Failure, Pulmonary Embolism, Multi-System Failure, COPD, ARDS, Asthma
12.8%	<i>of deaths were due to</i>	Pneumonia	<i>including</i>	Pneumonia/influenza
10.3%	<i>of deaths were due to</i>	Aspiration Pneumonia	<i>including</i>	Aspiration Pneumonia
9.8%	<i>of deaths were due to</i>	Sepsis	<i>including</i>	Septicemia, Bacterial, Shock, Urosepsis, Peritonitis
7.4%	<i>of deaths were due to</i>	Cancer	<i>including</i>	Wide variety of primary origin sites
3.4%	<i>of deaths were due to</i>	Stroke/CVA	<i>including</i>	Intercerebral Hemorrhage
2.5%	<i>of deaths were due to</i>	Genetic Disorder	<i>including</i>	Muscle diseases, etc.
2.5%	<i>of deaths were due to</i>	Renal/Kidney	<i>including</i>	Renal Failure chronic and acute
2.5%	<i>of deaths were due to</i>	Digestive System	<i>including</i>	Intestinal Obstruction, Liver Disease, volvulus

The 10 leading causes of death in 2009 (Table 11) are noted above. Heart disease remains the leading cause of death for the DDS population with respiratory disease, pneumonia, aspiration pneumonia and sepsis rounding out the top five.

Heart Disease

Heart Disease/cardiovascular disease remains the leading cause of death for the CT DDS population (29.9%). Cardiovascular disease is an umbrella term to describe any abnormal condition characterized by the dysfunction of the heart or blood vessels. Examples of diseases that fall within this category are congestive heart failure, cardiac arrhythmia, arteriosclerosis, ischemic heart disease, coronary artery disease, heart valve disease, hypertension, endocarditis, myocardial infarction, myocarditis, disease of the aorta, peripheral vascular disease and others.

* CT DDS receives certificates of death and death reports for all deaths reviewed.

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Section Five Continued

Table 12 provides an in-depth analysis of the cardiac deaths that were reviewed as part of the DDS mortality review process. The data reveal that more males than females died as a result of heart disease in FY 07, 08 and 09. However, in FY 09, unlike the prior two years, men who died as a result of heart disease lived longer than women.

Table 12
Deaths Due to Heart Disease

Year	Number of Male Deaths	Number of Female Deaths	Average Age Male	Average Age Female	Average Age
FY 07	23	19	59.5	75.9	66.9
FY 08	18	15	66.5	69.2	67.7
FY 09	21	20	61.8	60.2	61

As in the general population, many of the consumers who died as a result of cardiovascular disease had at least one or more identified risk factors prior to their death such as high blood cholesterol, high blood pressure, coronary artery disease, peripheral vascular disease, congenital heart defects, congestive heart failure, physical inactivity, obesity and diabetes mellitus.

In the general population over 83% of people who die of coronary heart disease are 65 or older⁵⁸ as compared with only 29% of individuals in the CT DDS population. Of the remaining cardiac related deaths in the DDS population group: twenty-four percent (24%) of the cardiac deaths occurred prior to the age of 50 years and 46% percent of the cardiac deaths occurred between the ages of 50-65.

There is a greater prevalence of congenital heart conditions and atrioventricular septal defects⁶⁰ found in people with Down syndrome. However, CT DDS data reveals that the incidence of cardiac deaths reported for people with Down syndrome was in line with the rest of the DDS population.

Respiratory Disease

The 2009 leading cause of death data demonstrates the significant impact of respiratory disease in the CT DDS population.

An analysis of the cases reviewed by the CT DDS mortality review process revealed that more men died as a result of respiratory disease/aspiration pneumonia/pneumonia than women and that they died at a younger age.

Table 13
Deaths Due to Respiratory Disease, Pneumonia and Aspiration Pneumonia

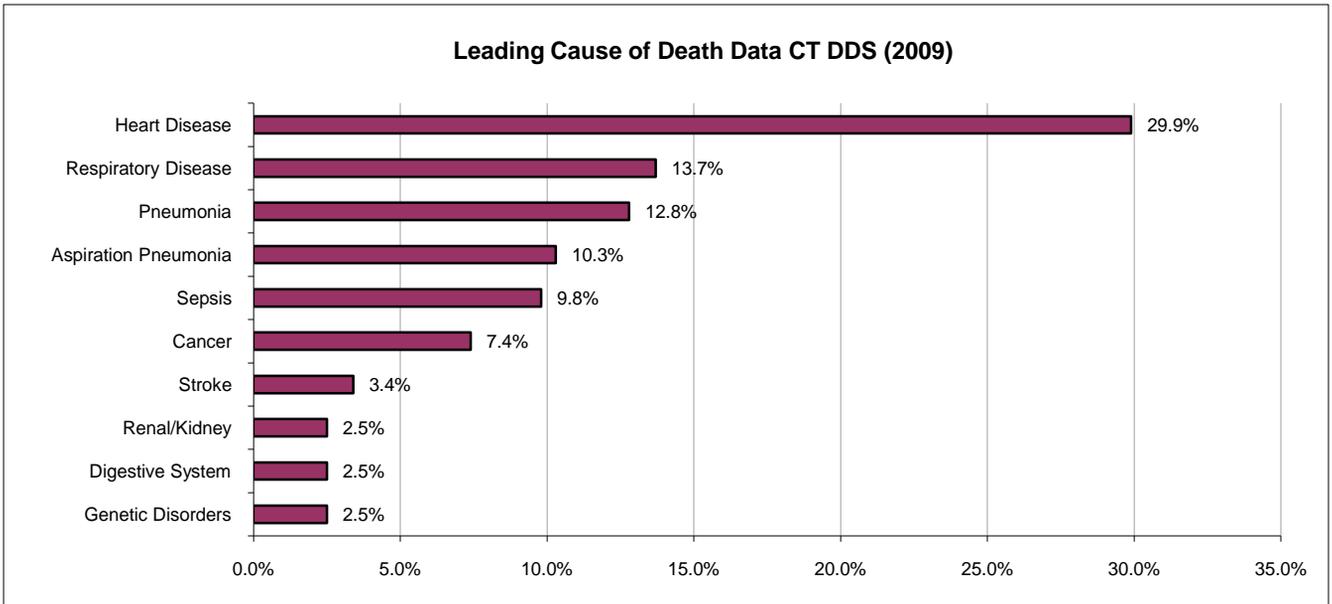
Year	Number of Males	Number of Females	Avg. Age of Males	Avg. Age of Females	Ave. Age
FY 07	24	34	60.1	69.7	65.7
FY 08	31	23	63.4	67.7	65.3
FY 09	32	23	60.4	65.9	62.7

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Section Five Continued

Figure 23



All diseases of the lung/respiratory system due to an identified respiratory disease process such as acute bronchitis, emphysema, asthma, pulmonary embolism, respiratory failure, COPD, ARDS pneumonia and aspiration pneumonia were responsible for 36.8% of all deaths in 2009 eclipsing the number of deaths caused by cardiac disease (29.9%).

The frequency of respiratory disease (specifically pneumonia and aspiration pneumonia) and the resultant high mortality rate seem to be closely related to the risk factors of immobility and dysphagia or swallowing dysfunction, restrictive pulmonary function due to curvature of the spine, cerebral palsy, genetic syndromes, hiatal hernia and other anatomical anomalies which are prevalent in the population served by DDS. The extraordinary relationship between respiratory disease, aspiration pneumonia and morbidity and mortality in the population of people with intellectual disabilities has also been identified and reported by other state ID/DD agencies.^{53, 55, 77, 78, 81, 82}

The incidence of mortalities related to respiratory diseases is even more striking in the DDS Down syndrome population illustrated by the fact that almost 70% of people with Down syndrome died as a result of respiratory failure, aspiration pneumonia or pneumonia.

Alzheimer's Disease

Alzheimer's Disease is not included in the CT DDS leading cause of death statistics because Alzheimer's Disease is rarely identified as an immediate cause of death or underlying cause of death on certificates of death or noted on CT DDS Death Reports. However, during the mortality review process it was determined that in 17% of the 133 deaths, the person had a diagnosis of Alzheimer's Disease at the time of their death. For comparison, in 2007 the MA DDS reported that 11.3% of all deaths resulted from Alzheimer's Disease.⁷⁷

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Section Five Continued

Table 14

Leading Causes of Death CT DDS

Rank	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005
1	Heart Disease 29.9%	Heart Disease 31%	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%
2	Respiratory Disease 13.7%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%
3	Pneumonia 12.8%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%
4	Aspiration Pneumonia 10.3%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%	Cancer 8%
5	Septicemia 9.8%	Pneumonia 8.6%	Pneumonia Aspiration 8.5	Septicemia 7.8%	Septicemia 5.6%
6	Cancer 7.4%	Septicemia 8.6%	Septicemia 6%	Pneumonia Aspiration 5.5%	Stroke 3.7%
7	Stroke 3.4%	Nervous System 3.7%	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%
8	Kidney/ Renal 2.5%	Kidney/ Renal 3.2%	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%
9	Digestive System 2.5%	Stroke 2.7%	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%
10	Genetic Disorder 2.5%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%

Based on 2009 calendar year data

Table 14 compares the top ten leading causes of death with CT DDS data from previous years. Other than heart disease as the leading cause of death in the CT DDS population there were many changes in the cause of death rankings compared to the 2008 data. For example: respiratory disease passed aspiration pneumonia to become the second leading cause of death. Pneumonia was the third leading cause moving up two notches, cancer dropped to the sixth leading cause from fourth, while septicemia went up to the fifth leading cause of death from the sixth. There were minor changes on a percentile basis for the leading causes of death (7-9). This year genetic disorder replaced nervous system as a top ten cause of death. Of note: Over the past three years accidental deaths did not make the top 10 causes of death. Respiratory disease, aspiration pneumonia and pneumonia as a cause of death once again represented over 1/3 of all CT DDS deaths.

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Section Five Continued

Leading Causes of Death for People with Down Syndrome

Table 15

FY 09

Primary Cause of Death/Down Syndrome

Respiratory Failure	15
Cardiac Arrest	7
Aspiration Pneumonia	3
Pneumonia	1
Subdural Hematoma	1
Total	27

It is estimated that between 300,000 and 350,000 people in the United States have Down syndrome. In the State of Connecticut approximately 2,400 people have Down syndrome. This number would represent 16% of the CT DDS population.

This year respiratory failure was the leading cause of death for persons with Down syndrome (55%) followed by aspiration pneumonia and cardiac arrest. (Table 15)

Since 2006 aspiration pneumonia and respiratory failure have accounted for 62% of all deaths for people with Down syndrome. (Table 16)

DDS mortality findings are also in line with other research studies that indicate that the life expectancy among adults with Down syndrome is about 55 years of age.^{15,16,19,20} The average age of death for people with Down syndrome in the CT DDS system is 57.2.

Based on the DDS Down syndrome and death data (Table 17) there is no appreciable difference in lifespan for those individuals with or without Alzheimer's Disease.

Although Alzheimer's Disease was rarely documented as a cause of death the majority of people with Down syndrome had a diagnosis of Alzheimer's Disease at the time of their death (70%). This data supports other research studies that found increased prevalence of Alzheimer's Disease in people with Down syndrome.

Table 16

FY 06 - FY 09

Primary Cause of Death/Down Syndrome

Respiratory Failure	36
Aspiration Pneumonia	24
Cardiac Arrest	23
Renal Failure	3
Gastrointestinal hemorrhage	2
Sepsis	2
Subdural hematoma	2
Asphyxia	1
Cancer	1
CVA	1
Liver Disease	1
Lymphoma	1
Pneumonia	1
Total	98

Table 17

Average Age of Death Data

	2008	2009
Down syndrome	58.3	57.2
Down & Alzheimer's:	59.4	57.8
Down without Alzheimer's:	55.2	57.1

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Section Five Continued

Analysis of Cancer Deaths

Table 18

FY 09

Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	2	61.3
Pancreas	2	71.6
Lymphoma	2	50.6
Breast	2	58
Bladder	1	96.1
Brain	1	64.1
Colon	1	39.5
Esophagus	1	82.9
Nasopharyngeal	1	63.2
Stomach	1	60.3
Unknown	1	46.6
TOTAL	15	62.4

In FY 2009 cancer was the sixth leading cause of death for people supported by the CT DDS

For FY 09 the distribution of cancers in men were pancreas (2), bladder (1), colon (1), esophagus (1), lung (1), lymphoma (1), and nasopharyngeal (1).

The FY 09 distribution of cancers in women were: breast (2), brain (1), lung (1), lymphoma (1), stomach (1) and unknown (1).

The average age of death for all cancer victims (62.4 years) exceeded the average age of death for all CT DDS deaths (57.1 years).

The rate of death due to cancer in the CT DDS population (1.1/1000) was lower than the rate of 2.4/1000 in the state of CT and 1.9/1000 nationally.^{2,80}

Over the past 4 years cancers have represented 9% of CT DDS mortalities.

Lung and pancreatic cancers continue to be the most common types of cancers over the past 4 years.

Table 19

FY 06 - FY09

Analysis of Cancer Deaths

Primary Site	Number of Deaths	Average Age at Death
Lung	12	62.1
Pancreas	7	69.8
Breast	5	60.4
Bladder	4	61.9
Colorectal	4	63.1
Stomach	4	65.3
Brain	3	68.4
Esophagus	3	70
Lymphoma non-Hodgkins	3	59.7
Prostate	3	79.7
Renal	3	49
Larynx	2	51.5
Liver	2	57
Lymphoma	2	65
Ovary	2	45.5
Adeno Carcinoma	1	46
Angiosarcoma	1	53
Aplastic Anemia	1	23
Cholagio	1	86
Endocrine/Adrenal Gland	1	61
Ethmoid Sinus	1	48
Gallbladder	1	60
Lymphatic/Hemotopoietic	1	73
Nasopharyngeal	1	63.2
Oral/pharynx	1	68
Parotid Gland	1	46
Testicular	1	63
Trachael/Bronchus	1	81
Unknown	4	61.9
TOTAL	76	62.3

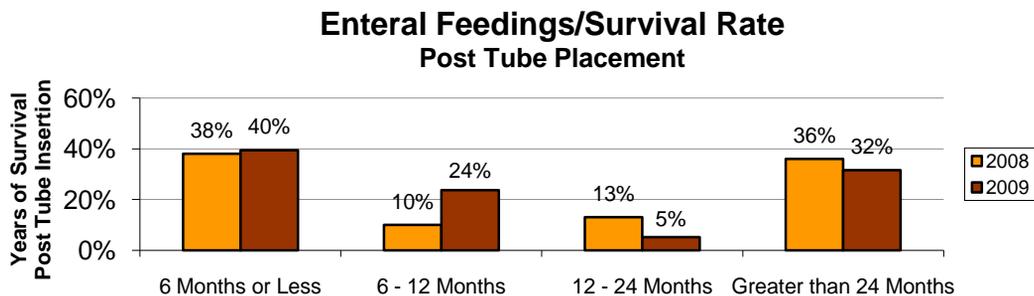
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Section Five Continued

Enteral Feedings

Figure 24



As a result of the CT DDS mortality review process and resulting data analysis the department has identified that there is a relationship between survival and initiation of gastrostomy or jejunostomy tube feedings. The data reveals that during the past three years 128 individuals were tube fed prior to their death. Ninety-nine individuals had a gastrostomy tube, 17 had a jejunostomy tube and 12 had a gastrostomy and jejunostomy tube.

In most cases the enteral feedings were initiated for one or more of the following reasons: recurrent aspiration pneumonia, malnutrition and/or dementia. In fact, 90% of these individuals had a history of recurrent pneumonia or aspiration pneumonia or dementia before insertion of the feeding tube.

In FY 09, 29% of the people reviewed (133) who died were fed enterally at the time of their death. Six month survival following placement of a feeding tube was 39.5% (15/38); 1-year survival was 23.7% (24/38); 2-year survival was 5.2% (26/38). Therefore, 68% (26/38) died within two years of initiating the tube feeding. In FY 08, 30% of the people reviewed (133) who died were fed enterally at the time of their death. Sixty-one percent died within two years of initiating the tube feeding. The CT DDS data enteral feeding data supports other research findings that suggest that enteral feedings do not prolong survival for the elderly and/or people who have significant cognitive or neurological conditions.^{41,42,45,46,48,50,69,70,71}

The immediate cause of death in the majority of these cases was attributed to pneumonia, aspiration pneumonia or respiratory failure. And within the CT DDS mortality population there did seem to be an increase in the incidence of pneumonia/aspiration pneumonia or risk of mortality associated with enteral tube feeding. Therefore, the DDS data seemed to validate other studies which suggest that people who require enteral feeding tubes have a significantly higher rate of pneumonia and pneumonia related death.^{38,39,42,48 66}

The gender and/or level of intellectual disability of CT DDS individuals who were tube fed did not have an impact on mortality. However, an individual's unique clinical profile did seem to be an important factor in predicting risk of mortality post artificial enteral nutrition.

•This preliminary analysis of the CT DDS mortality data suggests that the risk associated with tube feeding outweighs the benefits. In this regard the CT DDS data is consistent with other studies that failed to show that intervention by tube feeding is an effective treatment approach in supporting people who are on a dying trajectory due to a chronic illness.^{48,50,69,70,71} However, the lack of evidence based research to support the practice of feeding tube placement (G/J) in the ID/DD population suggests that further investigation would be of considerable importance to practitioners in this field.

* Based on data from all 133 cases reviewed by the CT mortality review process.

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SECTION SIX: BENCHMARKS

Mortality Rate Comparison

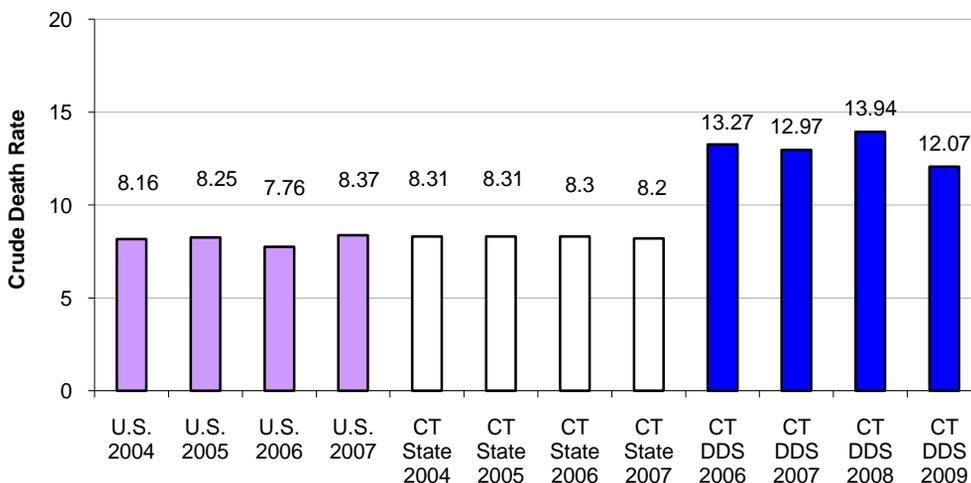
Benchmarks are standards by which similar items can be compared and allow the reader to place findings in context. Thus, the use of benchmarks including comparative data from other populations and/or from other state disability departments is an important mechanism for helping to understand analytical findings and trend data such as those presented in this report.

As mentioned in previous DDS Mortality Reports there are few relative benchmarks (data from other state agencies) available for use in comparing mortality data for persons with ID/DD and when data does exist, there may be differences in the way the data is reported and analyzed.

The overall CT DDS crude death rate of 12.07/1000 is higher than the rate of 8.2 in Connecticut (2007) and the rate of 8.04 in the general United States population (2007)^{2, 80}. This would be expected due to the many health and functional complications associated with intellectual disabilities.

Figure 25

Overall Death Rate
Comparison of Average Death Rates/1,000



While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc. ^{2, 11, 72, 73, 80}

In this report we use the term “average death rate” to reflect what is more commonly referred to as the “crude” death rate in mortality and epidemiological research. It is a measure of how many people out of every thousand served by CT DDS died within the fiscal year. It is determined by multiplying the number of individuals who died during the year times one thousand and dividing this number by the total number of individuals served by DDS during the same period of time.

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Table 20

Comparison Leading Causes of Death National, State of CT and CT DDS

Rank	US 2007	US 2006	US 2005	STATE CT 2007	STATE CT 2006	STATE CT 2005	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005
1	Heart Disease 25.4%	Heart Disease 25.9%	Heart Disease 26.5%	Heart Disease 25.3%	Heart Disease 25.5%	Heart Disease 25.9%	Heart Disease 29.9%	Heart Disease 31.0%	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%
2	Cancer 23.1%	Cancer 23.1%	Cancer 22.8%	Cancer 23.6%	Cancer 24%	Cancer 23.8%	Respiratory Disease 13.7%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%
3	Stroke 5.5%	Stroke 5.6%	Stroke 5.8%	Stroke 5%	Stroke 5.2%	Stroke 5.2%	Pneumonia 12.8%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%	Pneumonia Aspiration 12%
4	Respiratory Disease 5.3%	Respiratory Disease 5.1%	Respiratory Disease 5.3%	Respiratory Disease 4.7%	Respiratory Disease 5%	Respiratory Disease 5%	Aspiration Pneumonia 10.3%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%	Cancer 8%
5	Accidents 4.8%	Accidents 4.8%	Accidents 4.7%	Accidents 4.6%	Accidents 4.3%	Accidents 3.8%	Septicemia 9.8%	Pneumonia 8.6%	Pneumonia Aspiration 8.5	Septicemia 7.8%	Septicemia 5.6%
6	Alzheimer's Disease 3.1%	Alzheimer's Disease 3%	Diabetes 3%	X	X	X	Cancer 7.4%	Septicemia 8.6%	Septicemia 6%	Pneumonia Aspiration 5.5%	Stroke 3.7%
7	Diabetes 2.9%	Diabetes 2.9%	Influenza/ Pneumonia 2.9%	X	X	X	Stroke 3.4%	Nervous System 3.7%	Stroke 3.5%	Kidney/ Renal 4.4%	Accident 3.7%
8	Influenza/ Pneumonia 2.2%	Influenza/ Pneumonia 2.3%	Alzheimer's Disease 2.5%	X	X	X	Kidney/ Renal 2.5%	Kidney/ Renal 3.2%	Kidney Renal 3.5%	Accident 2.7%	Nervous System 3.3%
9	Nephritis/ Kidney 1.9%	Nephritis/ Kidney 1.8%	Nephritis/ Kidney 1.8%	X	X	X	Digestive System 2.5%	Stroke 2.7%	Digestive System 3%	Stroke 2.2%	Digestive System 1.4%
10	Septicemia 1.4%	Septicemia 1.4%	Septicemia 1.4%	X	X	X	Genetic Disorder 2.5%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%

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Section Six Continued

Leading Causes of Death Benchmarks: National, State of CT and CT DDS

Table 20 compares the top ten leading causes of death for people served by CT DDS with vital statistics benchmarks data for the State of Connecticut, and United States. Year over year data comparisons continue to demonstrate consistency in the leading causes of death data.^{2,11, 72, 73, 80}

Heart Disease: (Due to various cardiac diagnoses) is the number one cause of death for all of the referenced populations. As in past years the prevalence of cardiac disease is slightly greater in the DDS population at 29.9% versus and 25.3 in the CT general population and 25.4 nationally.

Respiratory Diseases: Is the second leading cause of death in the CT DDS population (13.7%). This category which includes influenza causes death in the CT DDS population at a rate more than 2 ½ times reported in the CT and national vital statistics data base (5%) and (5.3%) respectively .

Pneumonia: Is the third leading cause of death accounting for 12.8% of CT DDS deaths compared to <3% in the general CT and US population.^{2,11} Many of the multiple co-morbidities found in the CT DDS ID/DD population such as cerebral palsy, congenital syndromes, epilepsy, GERD, hiatal hernia, and immuno-deficiency disorders result in a compromised pulmonary system that makes this population vulnerable for developing pneumonia.

Aspiration Pneumonia: Is the fourth leading cause of death in the DDS population (10.3%) and as mentioned earlier in this report is unique to the ID/DD population due to many factors including the prevalence of dysphagia, Down syndrome, Alzheimer's Disease and enteral feedings. In comparison, aspiration pneumonia is not reflected in the state of CT or national vital statistics as one of the top ten leading causes of death.

Septicemia: Originating from various sites and usually acute in onset is the fifth leading cause of death in the CT DDS population resulting in 9.8% of deaths while only 1.4% of deaths in the US general population are caused by sepsis.^{2,11}

Cancer: Is the sixth leading cause of death in the CT DDS population responsible for almost 7.4% deaths. Unlike the previously mentioned leading causes of death, cancer in DDS occurs less frequently in the CT DDS population than in the CT (24%) and national (23.1%) general populations.

Accidental Deaths: In calendar year 2009 the percent of deaths resulting from accidents in the CT DDS system (1%) did not make the top 10 leading causes of death and once again was lower than the number of accidental deaths reported in the 2007 CT population (4.6%)² and US population (4.8%)

Caution: While comparison of CT DDS mortality data with benchmarks from the general population (state and national) are of interest, they are not very practical for direct comparison purposes due to differences in population characteristics, adjusted age and statistical methods etc. For example the special health concerns (co-morbidities) inherent in people with intellectual disabilities are related to a greater mortality rate. Also, many individuals in the CT DDS system had a diagnosis of dysphagia and or gastroesophageal reflux disease at the time of their death. Both of which have been linked to aspiration pneumonia, respiratory failure, sepsis and death in the ID/MR population.^{6,31,45,47,49,50}

Seasonal variations in mortality require consistency when conducting comparative analysis and, therefore, the previous data regarding leading causes of death is based on the calendar year 2009. Leading cause of death data for the calendar year will allow benchmark data from CT DDS to be consistent with Connecticut and national mortality benchmarks developed for the general population (2007) calendar year.

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Benchmarks Other States

The Massachusetts Department of Developmental Services (MA DDS) reviews the causes and circumstances of the death of individuals who receive DDS supports through an established process for death reporting and mortality reviews similar to the CT DDS. As part of this effort the University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research (CDDER) has prepared annual reports on mortality within this population of Massachusetts citizens since the year 2000. The Massachusetts DDS report represents population and mortality information for the period between January and December of 2007.⁷⁷

OF NOTE: In this section mortality data for the MA DDS will be presented with data from CT DDS. Since some of the CT DDS mortality statistics include children and MA DDS data does not, this will be noted in this section when making comparisons. It should be noted that the Massachusetts DDS system, although larger, is very similar to Connecticut's (e.g., population served, type of services and supports, organization). It is important that readers exercise caution when reviewing comparative information.

Mortality Rate Benchmarks

Table 21

Comparison of Crude Mortality Rates for Selected State MRDD Systems

Comparative Mortality Rates	MA DDS 2007	CT DDS 2009	TN DMRS FY 2005	VT FY 2005	OH 2006	OH 2008
Population Served	MR only	MR only	DD	DD	DD	DD
Age Range (for computing rate)**	adults only (18+ yrs)	children and adults	-----	children and adults	children and adults	children and adults
No. Deaths	416	188	108	26	746	751
Mortality Rate (no./1,000)	17.6	12.1	10	8.4	9.5	9.5

Findings from five states' DD/MR mortality reports above include information on crude mortality rates.^{52, 77, 78, 79} As mentioned in the MA DDS report, differences in population characteristics, age ranges included in the analysis, age distribution of persons served, service definitions, reporting time periods and requirements and the general absence of national conventions for organizing and reporting mortality data, make direct comparisons among state MR/DD systems difficult.

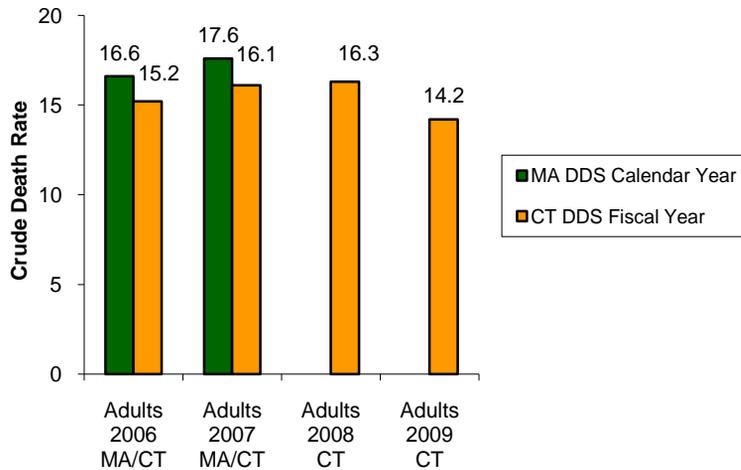
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Figure 26

Overall Death Rate
Comparison of Average Death Rates



Crude death rate above based on adult population (18+).

Crude mortality rates for CT and MA are similar for comparable adult population groups.

Table 22

Comparison of the Percentage of Deaths by Gender
CT DDS and MA DDS

Gender	Measure	CT DDS 2009	MA DDS 2007
Male	Percentage of Deaths	54.8%	52.6%
	Death Rate	11.5	16.9
	Ave. Age of Death	58	60
Female	Percentage of Deaths	45.2%	47.4%
	Death Rate	12.8	18.5
	Ave. Age of Death	56.1	64.2

Note: Death rate for CT DDS includes children and adults
Death Rate for MA DDS includes only adults

*MA DDS gender and mortality data is based on calendar year data

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Residential Benchmarks

Table 23

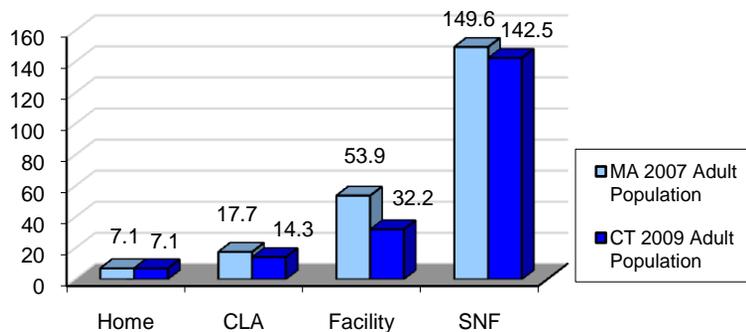
Comparison of the Mortality Rate by Residential Setting For the Massachusetts DDS and Connecticut DDS

Type of Residential Setting	Mortality Rate (per thousand)	
	MA DDS 2007	CT DDS 2009
At Home/Family Independent & Supported Living	7.1	5.6*
Community Group Home Community Training Home	17.7	13.9
Regional Center Facility-ICF/MR	53.9	32.1
Nursing Facility	149.6	142.2

Differences in the population characteristics within residential settings supported by the MA DDS and CT DDS make direct comparisons less than ideal. For example MA DDS does not include children in their population base for calculating mortality rates. However, there are distinct similarities in types of support settings between the two service systems which make crude mortality rate comparisons of interest.* For example less than 2% of the CT CLA population are children, and of the people living in CT DDS facilities/ICF programs, 99.5% are adults. Therefore these populations are almost identical and can be used for comparison purposes, for example the facility/ICF/MR mortality rates. Crude death rates in CT DDS by residential service types appear to be very consistent with available benchmark data as reported in Massachusetts DDS Mortality Report. General patterns are similar, with the highest mortality rates in support settings where individuals require a higher level of supervision.

Figure 27

Comparison of Death Rates CT DDS vs. MA DDS By Where People Live



*Where not specified the CT DDS mortality data is based on all people served by the CT DDS (children & adults). MA DDS data is for the adult population only. As with other data presented in this report, caution must be exercised in reviewing this information due to the relatively small sample size (number of deaths) in certain residential types and causes of death. Differences that occur year to year may not be statistically significant.

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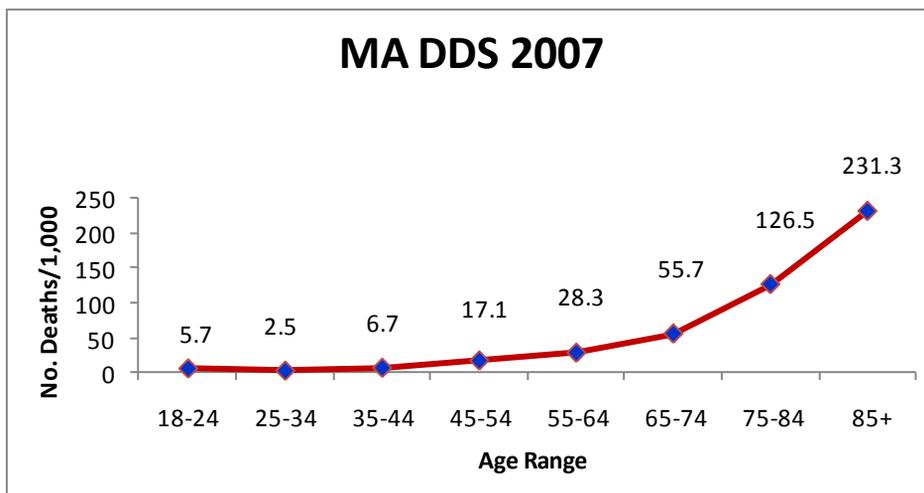
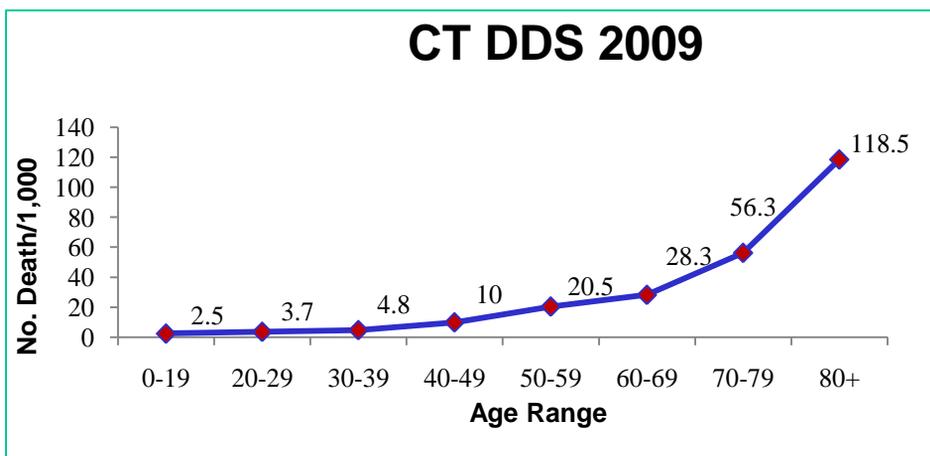
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Mortality and Age Benchmarks

Crude mortality rates by age range are presented for CT DDS and MA DDS, and although the age range used by each state differs and a direct comparison is not possible a common pattern is apparent with the mortality rate increasing with age. In both states the death rates increase markedly after the age 60-65 years. Again differences in data distribution make it difficult to draw direct comparisons.

Figure 28

CT DDS and MA DDS Mortality Rates by Age



When age is adjusted for the CT DDS population to reflect only individuals over the age of 18 years, the CT DDS average age of death of 58.9 years is slightly lower than the MA DDS average age of death of 62 years.

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Section Six Continued

Table 24

Leading Causes of Death CT, MA and Ohio

Rank	CT DDS 2009	CT DDS 2008	CT DDS 2007	CT DDS 2006	CT DDS 2005	MA DDS 2007	MA DDS 2006	MA DDS 2005	OHIO MRDD 2008	OHIO MRDD 2007
1	Heart Disease 29.4%	Heart Disease 31%	Heart Disease 29.1%	Heart Disease 25.4%	Heart Disease 35%	Heart Disease 16.8%	Heart Disease 21.9%	Heart Disease 16.4%	Heart Disease 18.9%	Heart Disease 18.5%
2	Aspiration Pneumonia 16.2%	Aspiration Pneumonia 15%	Respiratory Disease 18%	Respiratory Disease 18.2%	Respiratory Disease 24%	Cancer 13.4%	Alzheimer's 14.4%	Cancer 12%	All Other Causes 16.5%	All Other Causes 16%
3	Respiratory Disease 13.7%	Respiratory Disease 12.3%	Cancer 11%	Pneumonia 14.4%	Aspiration Pneumonia 12%	Septicemia 13.2%	Cancer 9.9%	Influenza/ Pneumonia 10.8%	Pneumonia 12.4%	Pneumonia 10.2%
4	Pneumonia 8.8%	Cancer 10.7%	Pneumonia 8.5%	Cancer 11%	Cancer 8%	Alzheimer's Disease 11.3%	Aspiration Pneumonia 8.4	C-P Arrest Seizure 10.8%	Cancer 10.1%	Cancer 9.7%
5	Cancer 7.8%	Pneumonia 8.6%	Pneumonia Aspiration 8.5	Sepsis 7.8%	Sepsis 5.6%	Aspiration Pneumonia 10.7%	CLRD 5.7%	Aspiration Pneumonia 9.3%	Aspiration Pneumonia 9.7%	Congenital Disease 9.5
6	Septicemia 7.4%	Septicemia 8.6%	Septicemia 6%	Aspiration Pneumonia 5.5%	CVA 3.7%	Unintentional Injury 6.2%	C-P Arrest Seizure 5.5	Alzheimer's Disease 8.60%	Congenital Disease 6.4%	Aspiration Pneumonia 9.9%
7	Genetic Disorder 3.9%	Nervous System 3.7%	CVA 3.5%	Kidney/ Renal 4.4%	Accident 3.7%	C-P Arrest Seizure 3.4%	Stroke 5.2%	Septicemia 5.9%	X	Infection 5.8%
8	Stroke 3.4%	Kidney/ Renal 3.2%	Kidney/ Renal 3.5%	Accident 2.7%	Nervous System 3.3%	Influenza/ Pneumonia 3.4%	Septecemia 5.2%	CLRD 4.6%	X	Seizure 3.9%
9	Kidney/ Renal 1.9%	Stroke 2.7%	Digestive System 3%	CVA Stroke 2.2%	Digestive System 1.4%	Stroke 2.8%	Influenza Pneumonia 3.9	Stroke 4.2%	X	Accidents 3.80%
10	Digestive System 1.9%	Digestive System 1.6%	Nervous System 2%	Nervous System 2.2%	Kidney Renal <1%	Congenital Anomalies 2.8%	Unintentional Injuries 3.7	Unintentional Injuries 3.4%	X	Lung Disease 3.6%

A review of state mortality data from CT DDS, MA DDS and Ohio DMRDD 17, 44, 51, 52, 54, 77, 78, 82, 82 demonstrate similarities in leading cause of death data for people with ID/DD. Heart disease remains the leading cause of death for people with ID/DD in the states noted in Table 24 above. Respiratory disease, pneumonia and aspiration pneumonia are a significant leading cause of death in the ID population.

Differences in state cause of death data and ranking may be due to the differences in the population analyzed (age range) and variations in immediate cause of death documented by practitioners on the certificate of death. For example, CT DDS mortality data includes children (5% of all reported deaths) and adults.

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SECTION SEVEN: SUMMARY MORTALITY CASE REVIEW FINDINGS

The CT DDS mortality review process has evolved into a powerful quality assurance system for ensuring the delivery of optimal health care oversight and services in the CT DDS. The regional and state recommendations regarding health care oversight and standardization of health care practices for professional and non-professional staff have improved basic health care services and mitigated health related risk. The impact of mortality findings and recommendations has been observed within DDS and has extended to community based health care providers including practitioners in private practice licensed nursing facilities, acute care hospitals, hospice providers, health and dental clinics and other state agencies.

Table 25

Mortality Case Review Summary (FY 2009)

<i>Death Reviewed By Regional Committees</i>	<i>Cases Closed at Regional Level</i>	<i>Cases Referred and Reviewed By IMRB</i>	<i>QA Cases Closed by Region IMRB Review</i>	<i>Total Cases Reviewed By IMRB</i>
133	94 (71%)	39 (29%)	16 (12%)	55 (41%)

Table 25 above provides a summary of all deaths reviewed by the CT DDS Mortality Review Committees. Seventy-one percent of the 133 cases reviewed were closed by local regional mortality committees. The regional committees referred 39 mortality cases to the state Independent Mortality Review Board for further review. The reasons for the case referrals are noted in Table 26 (below).

The CT DDS Mortality Review Process requires that at least 10% of all cases that are closed at the regional level are reviewed by the Independent Mortality Review Board (IMRB) for quality assurance purposes. This year the IMRB reviewed 12% of cases closed by regional mortality committees.

Table 26

Cases Referred to IMRB (39)	
Medical/Health Care	22
Post mortem examination	14
Pending Abuse/Neglect Investigations	3

The DDS Commissioner reviews all cases that are reviewed by the IMRB.

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Section Seven Continued

CT DDS Mortality Review: General Findings

Predictors of Mortality in the ID Population

- age
 - mobility status
 - the need for special assistance when eating
 - sudden or progressive weight loss
 - level of intellectual disability
 - a distinct cluster of co-morbidities
 - chronic aspiration pneumonia
 - pneumonias that result in hospitalization
- Health care coordination by registered nurses is an essential support for the ID/DD population who are at risk for chronic and acute health conditions. Timely nursing assessment results in appropriate referral and treatment by medical practitioners.
 - The premature onset of acute and chronic health issues which lead to morbidity and mortality in people with ID presents a unique challenge to caregivers.
 - The CT DDS process for reviewing advanced life directives including the withholding of cardiopulmonary resuscitation (DNRs) provides the team with a foundation for quality end of life planning.
 - End of life planning that included hospice services and supports allowed many individuals with irreversible or terminal conditions to remain in their home or current residence.
 - CT DDS mortality cases referred to the CT Department of Public Health resulted in improvements in healthcare facility and/or health care practitioners standards of practice which we expect will ultimately advance the quality of care for people with ID/DD.
 - DDS Health and Nursing Standards and Protocols and other quality improvement initiatives developed as a result of the mortality review process have been adopted and implemented by provider agencies.
 - Consumers living in their own home or receiving individualized supports benefit from health education and training that focuses on health promotion and disease prevention.
 - Post mortem examinations are a valuable tool to confirm the cause and manner of death in cases where the cause of death was not immediately determined.
 - Health care practitioners continue to benefit from continuing education opportunities that focus on the special health needs of persons with intellectual disabilities.
 - Training topics were identified from IMRB findings and have been implemented for nursing and direct care staff by provider agencies.
 - From a resource and operational standpoint the “aging in place phenomenon” within the ID/DD population presents a future challenge for the CT DDS service system and for all care providers.
 - Enteral feedings do not prolong survival and may not improve the quality of life for individuals with intellectual disabilities.
 - The aging Down syndrome population requires specialized and comprehensive supports.
 - As a result of the mortality review process the quality of supports for people served by the CT DDS service system have improved.

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Section Seven Continued

Examples of CT DDS Mortality Findings and Quality Initiatives

<u>Areas of Review/Findings</u>	<u>Quality Initiatives</u>
Professional nursing care and coordination	Investigation recommendations regarding scope of nursing practice implemented. Continue to collaborate with CT Board of Examiners for Nursing to implement improvements in this area.
Hospital Emergency Department evaluation and treatment.	Timely evaluation and treatment by ED practitioners due to ongoing collaboration between DDS nursing staff, ED managers and physicians.
Documentation Standards	Best practice standards developed for documenting vital medical information, treatment decisions, diagnostic testing or physical examination findings .Nursing assessments disseminated to all clinicians within DDS service system.
Reporting of Death and Abuse/Neglect Investigations	All deaths were reported to CT DDS according to critical incident and death reporting procedure. Investigations were initiated in a timely manner.
Hospital Discharge Planning	Nursing Standard for Discharge Planning finalized. DDS continuing audit of coordination of supports post discharge.
Professional Nursing Services	Standardization of nursing role in various residential support systems. Professional nursing quality committee meets regularly to develop health and nursing best practice standards/procedures.
Nursing / Medical/Dental Shortage in ID/DD Field	CT DDS established clinical internships with several schools of nursing BSN and LPN technical programs. Orientation for nursing staff, DDS health and dental staff collaborating with hospital medical staff, and dental and medical schools.
Registered Nursing On Call System	Standardization and improvement in the implementation of nursing on call systems.
DNR (Do not resuscitate)	DDS continues to thoroughly review anticipated DNR requests per CT State Statute and DDS procedures
Post Mortem Examinations	Deaths reported to the Office of the Chief Medical Examiner per Protocol post mortems requested for all deaths of concern to the DDS
Medical and Health	<p>A Health Standard for routine preventive healthcare was developed.</p> <p>Nursing care plans consistently include pain management protocols where applicable.</p> <p>CT DDS registered nurse monitors and reviews the quality of care provided for consumers residing in licensed nursing facilities.</p>

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Section Seven Continued

Examples of IMRB Findings and CT DDS Quality Initiatives

<u>Areas of Review/Findings</u>	<u>Quality Initiatives</u>
Medical and Health	<p>IMRB Tracking System was established to monitor the progress of mortality review findings and recommendations.</p> <p>Dysphagia and swallowing risk training is provided annually for all staff – public and private.</p> <p>DDS North Region Managed Health Care Pilot Program was implemented to address the health issues of people receiving less than 24 hour supports</p> <p>A new waiver service for Health Care Coordination was developed to address complex health needs of people who live in their own homes with less than 24 hour support.</p>
Medication Administration	<p>The CT DDS Medication Administration Certification Program continues to provide a high level of quality and oversight. There were no mortalities related to the administration of medication by certified non-licensed or nursing staff.</p>
Oral Health	<p>The increased access to and quality of dental services for people with ID was evident due to addition of the DDS Dental Coordinator. The level of interagency collaboration to increase the capacity of dental services for people with intellectual disabilities increased significantly.</p>
Increased Monitoring and Oversight	<p>Increased monitoring by DDS Quality Management as a result of IMRB findings improved the quality and supports for people in the CT DDS service system.</p>
Interagency sharing of Health Records/ Information	<p>Protocols have been established with community based health care providers (hospitals, nursing facilities etc.) which ensure the timely and accurate sharing of clinical information.</p>

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APPENDICES

- Appendix A: Overview of DDS Population**

- Appendix B: DDS Consumers by Residential Setting
DDS Population by Age**

- Appendix C: Percentage Population by Age Ranges
Level of Intellectual Disability**

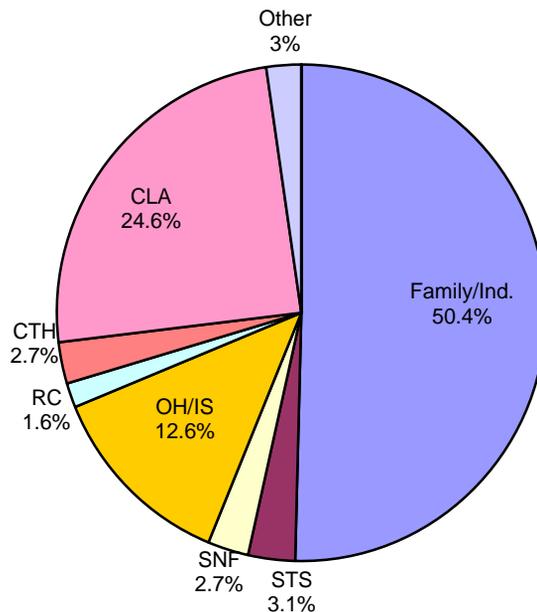
- Appendix D: Age Category and Residence
Consumers by Program Type**

APPENDIX A

Overview of DDS Population

Intellectual Disability is a developmental disability that is present in about 1% of the Connecticut population. In order for a person to be eligible for DDS services they must have significant deficits in intellectual functioning and in adaptive behavior, both before the age of 18 yrs. As of June 30, 2009 **15,390** individuals with intellectual disability were being supported by the department.

Overview of DDS Population Percentage by Setting



Half of the people served by CT DDS live at home with their family. One third receive support services provided in community living arrangements (CLAs), community training homes (CTH), regional centers (RC) and a campus program, Southbury Training School (STS). Approximately 13% of the DDS population receive individualized home supports (OH/IS). The remainder (5%) of the people are supported by other state or local government and/or private entities including licensed nursing facilities (SNF), the CT Department of Mental Health and Addiction Services, the CT Department of Children and Families, the CT Department of Corrections and residential schools.

APPENDIX B

DDS CONSUMERS BY RESIDENTIAL SETTING FY 08 - FY 09

Type of Support	2009		2008		2008 - 2009
	# of Consumers	Percent	# of Consumers	Percent	% Change
Family	7,758	50%	7,688	50%	1.0%
CLA (Group Home)	3,781	24%	3,716	24%	1.7%
Own Home/Ind. Services (OH/IS)	1,945	13%	1,932	13%	1.0%
Training School	480	3%	497	3%	(-3.4%)
Other	353	2%	463	3%	(-23.8)
Community Training Home (CTH)	413	3%	399	3%	3.5%
SNF	417	3%	312	2%	33.7%
Regional Center (RC)	243	2%	263	2%	(-7.6%)
TOTAL	15,390	100%	15,270	100%	

DDS Resident Population by Age 2005 - 2009

	2009	2008	2007	2006	2005
Children (0-19)	3,576	3,594	3,575	3,663	3,766
Adults (20 - over)	11,814	11,676	11,573	11,355	11,177
TOTAL ALL AGES	15,390	15,270	15,148	15,018	14,943

Adults (55 - over)	2,779	2,628	2,587	2,470	2,397
Adults (65 - over)	1,050	1,005	991	957	954

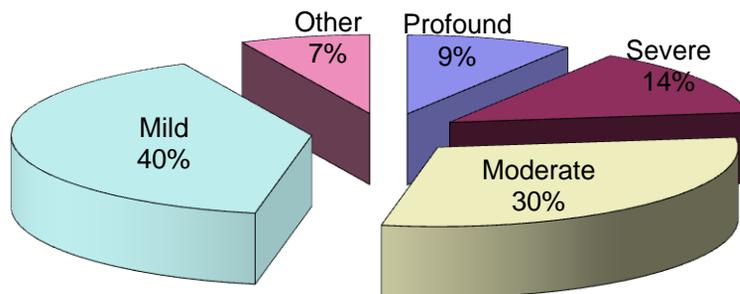
APPENDIX C

Percent Population by Age Ranges

FY 2009

AGE RANGE	TOTAL	% OF TOTAL
Age 0-19	3,576	23.2%
Age 20-29	3,170	20.6%
Age 30-39	2,072	13.5%
Age 40-49	2,579	16.8%
Age 50-59	2,202	14.3%
Age 60-69	1,169	7.6%
Age 70-79	436	2.8%
Age 80+	186	1.2%
TOTAL	15,390	100%

CT DDS Population - Level of Intellectual Disability



APPENDIX D

AGE CATEGORY AND RESIDENCE

FY 2009

Res type	Children (0-19)	Adults (20-64)	Older Adults (65+)	TOTALS
CLA (Group Home)	128	3,269	384	3,781
SNF	1	171	184	356
Campus	0	328	152	480
Own Home/Individualized Services	5	1,780	160	1,945
Other	191	182	41	414
Family Home	3,237	4,448	73	7,758
CTH (Community Training Home)	13	348	52	413
Regional Center	1	238	4	243
TOTAL	3,576	10,764	1,050	15,390
PERCENT	23%	70%	7%	100%

Consumers Age 19 - 64 Years

By Program Type

SNF	48%
STS	68%
CTH	87%
CLA	90%
OH/IS	92%
Family/Independent	99%
RC	98%

Consumers over the Age of 65

By Program Type

SNF	52%
STS	32%
CTH	13%
CLA	10%
OH/IS	8%
Family/Independent	1%
RC	2%